Health and Social Care Committee

Meeting Venue:
Committee Room 1 – Senedd

Meeting date:
Thursday, 12 June 2014

Meeting time:
09.15

Cynulliad
Cenedlaethol
Cymru
National
Assembly for
Wales

For further information please contact:
Helen Finlayson
Committee Clerk
029 2089 8600
HSCCommittee@wales.gov.uk

Agenda

1 Introductions, apologies and substitutions

2 Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan: Evidence session 1 (09.15 – 10.10)

(Pages 1 – 42)

Dr Martin O'Donnell, Royal College of General Practictioners
Alisa Hayes, Royal College of Nursing
Professor John Chester, Royal College of Physicians

3 Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan: Evidence session 2 (10.10 – 11.05)

(Pages 43 – 45)

Rachel Hargest FRCS, British Association of Surgical Oncologists
Dr Martin Rolles, Royal College of Radiologists

Break (11.05 - 11.15)

4 Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan: Evidence session 3 (11.15 - 12.10)

(Pages 46 - 50)

Emma Greenwood, Cancer Research UK
Dr Alison Parry-Jones, Wales Cancer Bank

Lunch (12.10 - 13.10)

5 Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan: Evidence session 4 (13.10 - 14.00)

(Pages 51 - 91)

Susan Morris, Macmillan Cancer Support
Simon Jones, Marie Curie Cancer Care
Dr Ian Lewis, Tenovus
Linda McCarthy, Wales Cancer Alliance

6 Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan: Evidence session 5 (14.00 - 15.00)

(Pages 92 - 103)

Dr Hamish Laing, Abertawe Bro Morgannwg University Health Board
Mr Damian Heron, Betsi Cadwaladr University Health Board and the North Wales Cancer Network
Dr Sian Lewis, Hywel Dda University Health Board
Dr Tom Crosby, Velindre NHS Trust and the South Wales Cancer Network

7 Papers to note (Pages 104 - 144)

By virtue of paragraph(s) vi of Standing Order 17.42

Agenda Item 2

Document is Restricted

National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from RCGP Wales – CDP 14

RCGP WALES Royal College of General Practitioners

Royal College of General Practitioners Wales
Regus House
Falcon Drive
Cardiff Bay
Cardiff
CF10 4RU

Committee Clerk
Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA.

17 March 2014

RE: Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Please find attached comments from RCGP Wales on the Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.

Yours Sincerely

Dr Paul Myres
Chair, RCGP Wales

Response to the inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

The Royal College of General Practitioners (RCGP) is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the 'voice' of GPs on issues concerned with education, training, research, and clinical standards. Founded in 1952, the RCGP has over 49,000 members, 1,915 in Wales, who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.

The Royal College of General Practitioners in Wales (RCGP Wales) welcomes the opportunity to contribute to this inquiry.

We will address this by looking at the outcome measures in the Cancer Delivery Plan.

Outcome 1 – People are aware of and are supported in minimising their risk of cancer through healthy lifestyle choices.

- more people are supported to quit smoking;

We are aware that there has been a lot of effort in Primary care through QOF to assess the smoking habits of the population and to offer advice where possible. The support from Pharmacy colleagues and from Stop Smoking Wales campaigns has been excellent but sadly sparse in places and needs better support. Delays in access to support services mean lower success rates in cessation.

- more people are aware of the health harms of smoking, consumption of alcohol above recommended limits and the broader benefits of physical activity and healthy eating;

There are ongoing good support programmes both Nationally (at relevant times, for example Christmas) and locally. However, the availability of cheap alcohol in supermarkets remains a major concern, especially for the younger 'binge' drinkers. The cost of healthy foods is also a concern with many people choosing unhealthy alternatives due to cost.

- more people achieve a healthy weight through weight management support;

There is an increasing awareness in the public of weight issues, but a significant lack of Primary and Community support with regard to access to dietetics or exercise on prescription programmes.

- more people are physically active as a natural part of their everyday life and undertake sufficient physical activity to benefit their health.

It is difficult to encourage people with multiple co-morbidities to undertake exercise programmes unless freely available and tailored to their individual capabilities.

Outcome 2 – Cancer is detected quickly where it does occur or recur

- easier access to primary care services;

Patients will be seen in Primary care, but due to the lack of funding, services have tended to constrict rather than expand. As more services move from secondary care into community settings without the funding following, these impact on potential access further. There needs to be an expansion of Primary care provision to ensure easier access. Patients with 'acute' *or ‘urgent’ problems will be seen on the day, but others will have a wait for routine appointments due to capacity issues. This does not engender the easy presentation of early symptoms.*

• more accessible information and support services provided through local pharmacies;
This is an area where development has taken place depending on the interest and engagement of local pharmacists. Sadly the bigger municipals with the use of frequent Locums do not engage as well in this regard.

• more clinical support available 24 hours a day, 365 days a year;
The cancer networks ensure access to an oncologist and also to palliative care consultants both in hours and out of hours, and is a greatly improved service.

• more direct access to diagnostics for GP;
This is dependant on locality, with some guidelines and pathways agreed for referral for access, monitored and managed by the radiology services. This is understandable as the resources are limited and need to be used sensibly. However, the ability to organise such scans before a secondary care appointment occurs would avoid unnecessary delays.

• a greater range of local services meaning less need to travel, particularly for diagnosis and care after treatment;
Again this is variable, with several areas of good practice working with locality groups. However, due to the need for centralisation of specialist services, this has resulted in longer journeys for some patients but presumed better quality and outcomes. Care after treatment in local settings has improved with the help of the Macmillan and Marie Curie services and specialist cancer care nurses who ensure care plans are in place and proactive planning occurs with the relevant GP and Out of Hours providers.

• take up of population screening in line with programme targets;
Encouragement and reminders are constantly done in Primary care.

• prompt and appropriate access to evidence based assessment and treatment to increase the chance of cure and reduce side effects;
This is much improved, with awareness of referral to treatment targets and the Cancer Care Standards. Initial assessment can, however, be delayed in some specialities e.g. bowel, with assessment questionnaires being sent out to patients and categorisation of urgency only occurring when they are returned (or not).

• more information on reducing the risk of developing cancer, recognising symptoms suggestive of early cancer and what services to expect to be available by telephone and on-line;
Information on line is readily available but less so via telephone unless through NHS Direct. Local services are well publicised on the relevant hospital websites. Recent health promotion campaigns via the media have encouraged patients to seek early advice for symptoms such as chronic cough, bloating etc; and can lead to increased anxiety and requests for referral which are hard to manage in this current economic environment.

- more men accessing healthcare as there is evidence their uptake can be lower than needed.

This remains difficult as men are reluctant to be seen as weak or needy and historically don't present until later in their symptomatology.

Outcome 3 – People receive fast, effective treatment and care so they have the best possible chance of cure.

Generally once the diagnosis is made, the treatment course, planning and implementation is usually fast and efficient. There are exceptions due to complexity or lack of availability of sufficient consultant staff e.g. Urology.

- prompt and appropriate access to clinically and cost effective treatment offering people better chances of being cured of cancer;

This is determined by local Multi Disciplinary Teams which act effectively and refer exceptional cases to the Individual Patient Funding panels who work with Welsh Health Specialised Services Committee (WHSSC) and All Wales Medicines Strategy Group (AWMSG) to ensure that the best outcomes are determined for the population.

- people experience well co-ordinated services, which are compliant with national standards and guidelines, safe, sustainable and available as locally where possible;

Co-ordination of care remains a problem because despite the use of key workers the flow of information, discharge summaries and treatment plans from secondary to primary care is still inefficient and often at times lacking completely or arrives too late to be useful. Local pathways are often determined by secondary care and rolled out to Primary care with little active consultation or thoughts for the practicalities involved, which can lead to a reluctance to use them if they are time consuming.

- specialist hospital cancer care in centres of excellence that match or surpass the best and seamlessly connected with local cancer services;

The cancer centres have focussed excellent care by centralising services and are to be praised for the service they deliver and the quality of staff employed. However local delivery of services remains patchy due to capacity issues.

- flourishing cancer research to improve treatment and making NHS Wales an attractive place to live and work for high calibre clinicians;

Health Boards and Universities do seem to be working together to audit activity and demand and to help with the clinical research trials available.

- more patients participating in clinical trials.

This option does appear to be more readily available to patients and most centres have several research staff to explain the meaning , risks and impacts of such trials.

Outcome 4 – People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer

- everyone is treated with dignity and respect;

generally the standard of care and compassion is high during the active treatment phase, but more work needs to be done to improve end of life care and support for families and patients.

- services are available as locally as possible;

This is limited by geography and capacity issues.

- people have access to timely information so they understand their condition and what to look out for and what to do and which service to access should problems occur;

This has improved due to available websites and easier printing of useful material in a primary care setting. Hospital information services tend to be well thought out and useful for patients and carers.

- every patient has a Key Worker who co-ordinates care and support in partnership with them;

Generally this happens, but better links with the community need to be formed as the key worker is often secondary care based for the treatment plan but failures of 'hand over' to a new community based key worker need to be improved.

- people's clinical and non clinical needs as a consequence of cancer are assessed and recorded in a care plan and services designed around meeting those needs;

There is still poor co-ordination of services between health and social services around the patient, especially for those based in residential and nursing care homes.

- care plans are written and shared with the person involved and reviewed on an ongoing basis;

When care plans are done this usually happens.

- follow up care given in the most appropriate place for the patient and not the service. Increasingly this should be in primary care.

This is difficult due to the overstretched capacity in Primary Care and the need for a better developed community support and nursing service 24/7. The ability to empower primary care also needs to be addressed through ongoing education programmes.

- direct access to services for cancer patients in whom recurrent disease is suspected;

This is usually not a problem.

- best possible IT and communication links giving clinical staff fast, safe and secure access anywhere in Wales to the information needed to care for patients;

Still in development and roll out – but out of hours services have access through the Internet Health Records (IHR) to a summary of the patient's primary care records – this needs further expansion and development.

- more information for people tailored to meet their individual needs;

Information is available in a wide variety of languages and formats, but tends to be generic rather than individualised.

- transport to and from clinics and hospitals is easily accessible;

Problems remain in rural areas.

- patients and carers are involved in the design of services and people's views on services are sought regularly and acted on to ensure continuous improvement;
Service redesign and strategic development is consulted with relevant groups and with the CHC.

- transparently published information available on the performance of NHS cancer care in terms of safety, effectiveness and patients' views.
Usually useful and informative when published.

Outcome 5 – People approaching the end of life feel well cared for and pain and symptom free

- more people receive palliative and end of life care and support on a 24/7 basis;
This has improved, with better awareness and proactive planning. The availability of the 'orange boxes' for palliation in the out of hours period has improved care.

- specialist palliative care nursing is available 7 days a week;
Usually available and have been attached to local OOH services.

- people's needs and wishes, and those of their family, are clarified, clearly recorded and are a key guide to care provided;
More work needed to ensure that this happens in all cases as there remains a reluctance to broach this delicate subject with individuals.

- people whose symptoms have not improved after 48 hours are referred to specialist palliative care;
This usually happens.

- key information on all patients with advancing cancer is recorded on CaNISC and accessible to others who have clinical responsibility for the patient, including out-of-hours GP services, on a 24/7 basis;
This key information is not always available to GPs, but is accessible through the on call consultant Oncologist.

- less people being admitted unnecessarily to hospital;
Subjectively we believe that this is the case, but sadly, unnecessary admissions still happen due to lack of community support and services available.

- more people are able to die in the place of their choice;
Variable – again depending on level of local support services.

- NHS and Third Sector voluntary sector care is integrated and seamless;
This is improving and continues to be supported and funded by Health Boards.

- families have access to pre and post bereavement support appropriate to their age.
This seems to be better for paediatric care than adult, but has improved overall.

We believe that there has been a slow but steady improvement in the drive to achieve excellence in Cancer care in accord with the Quality delivery plan for the NHS in Wales 2012 – 16

Dr. M.A. O' Donnell
Vice Chair (Policy and External Affairs)
RCGP Wales

National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Royal College of Nursing – CDP 25

National Assembly for Wales Health and Social Services Committee Inquiry examining the progress made in implementing the Cancer Delivery Plan in Wales including:

- Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016;
- Progress made in reducing the inequalities gap in cancer incidence and mortality rates;
- The effectiveness of cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups;
- Whether patients across Wales can access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner;
- The level of collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams.
- Whether the current level of funding for cancer services is appropriate, used effectively and provides value for money.

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1. The RCN is the world's largest professional union of nurses, representing over 415,000 nurses, midwives, health visitors, nursing students and health care support workers, including over 24,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing. The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

2. The Cancer Delivery Plan like many of the Welsh Government Delivery Plans has a section on prevention. The RCN has consistently proposed that prevention activity by health professionals needs to be joined up and not disease specific. Despite concerted efforts to prevent ill health in Wales, inequalities in health are widening. The risk factors for many diseases are interlinked and are rooted in poverty and deprivation. This has to be recognised and addressed.

3. The RCN is an active member of the Wales Tobacco Control Alliance. The Welsh Government's Tobacco Control Action Plan, published in 2012, sets a target of reducing smoking prevalence rates to 16% by 2020, from a current prevalence rate that remains stubbornly high at 23%. This is clearly an ambitious target. As giving up smoking is a key step for individuals taking responsibility for their own health, and reducing their risk of developing cancer, it is essential to recognise that the Tobacco

Control Action Plan underpins the preventive element of the Cancer Delivery Plan as well as in a number of other Welsh Government plans.

4. At the last meeting of the Wales Tobacco Control Alliance, members were informed of the concerns that ASH Wales has in terms of the leadership, accountability and monitoring structures for both of these plans. The following issues need to be addressed in order to ensure that the targets set out in both plans are achieved:

- Clear leadership
- Buy-in from key delivery partners and stakeholders
- Consistent strategic representation on delivery boards
- A more formal and robust accountability structure

5. Nurses are in an ideal position to influence the people they interact with be it in primary prevention, secondary prevention or in teaching the promotion of self care and management. Midwives, health visitors, and school nurses have an obvious role to play in ensure that every child has a healthy start in life. It is vital though that all nurses and midwives promote every encounter with their patients as a public health encounter. If we are to close the gap in health inequalities and the burden of avoidable ill health then we must harness the full potential of the nursing workforce.

6. The Cancer Delivery Plan makes a commitment to deliver person-centred cancer care in Wales and 'people are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer'. Specifically it calls on LHBs to:
   - Assign a key worker to each person with cancer, from the point of diagnosis onwards, to coordinate their care;

   The Cancer Patient Experience Survey (CPES) 2013[1] identified that only 66% of patients responding had been given the name and contact details of their key Worker.

7. As highlighted in the report, the most striking finding of the survey relates to the impact of the Clinical Nurse Specialist (CNS). On almost all questions in the survey, patients who have a CNS are significantly more positive than patients who do not have access to a CNS.

   "It is clear that the presence of a CNS makes a substantial positive difference to the perceived quality of cancer services seen by patients. On 59 questions in the survey, patients who had a CNS were more likely to be positive about their care and treatment than patients who did not; and the scale of differences on many questions is very substantial. All of these differences are statistically significant.
   The most pronounced differences in view between those patients with a CNS and those without one in 2013 were in respect of verbal and written information, involvement, information on financial support, discharge information and post discharge care and emotional support."

8. At the Cross Party Group on Nursing and Midwifery in October 2013, Macmillan Cancer Support identified that there is a mismatch between the distribution of Clinical Nurse Specialists in Wales and the distribution of cancer incidents. The group also heard from a Clinical Nurse Specialist for Breast Cancer who was concerned that

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[1] http://wales.gov.uk/docs/dhss/publications/140117canceren.pdf

some patients with certain types of cancer still don't have access to a CNS. At the meeting of the Cross Party Group in February 2013, Assembly Members were told of circumstances where men in Wales were personally paying to receive specialist robotic surgery for prostate cancer in England as the surgery was not available in Wales. The RCN was pleased to see the Welsh Government decision to fund robotic surgery system for Wales capable of minimally invasive treatment of prostate cancer at Cardiff and Vale University Health Board in August 2013. It is important that patients in Wales have an equity

9. Nurse specialists provide direct patient care, play a vital role in educating patients about how to manage their condition and importantly, provide emotional support. They take a leading role in ensuring that patients get the best care possible. A number of independent studies have shown that specialist nurses are both clinically and cost effective. [2]

   The cost benefits generated by specialist nurses include:
   - reduced waiting times,
   - avoidance of unnecessary hospital admission/ readmission (through reduced complications,
   - post-surgery/enhanced symptom control/ improved patient self-management),
   - reduced post-operative hospital stay times,
   - the freeing up of consultant appointments for other patients,
   - services delivered in the community/at point of need,
   - reduced patient treatment drop-out rates,
   - the education of health and social care professionals,
   - the introduction of innovative service delivery frameworks,
   - direct specialist advice given to patients and families.[3]

10. Whilst the development of the role of the specialist nurse has been one of the most exciting innovations in nursing practice in recent times it is also one of the least understood and valued and as such are vulnerable in times of constrained public spending. An RCN (2008) highlighted that;
    - more than one third of specialist nurses reported that they had a vacancy freeze in place.
    - 47% reported that they were at risk of being downgraded and
    - 68% reported having to see more patients.

11. The RCN has recently published 'More than just a Number[4]' showing that in England, hidden within wider nursing workforce cuts is a significant loss and devaluation of

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[2] Epilepsy Action (2010) *Best care: the value of epilepsy specialist nurse*. http://www.sudep.org/wp-content/uploads/2010/07/EpilepsySpecialistNurse-Report-2010.pdf

[2] Parkinson's UK (2011) *Parkinson's nurses- affordable, local, accessible and expert care: a guide for commissioners in England*. http://www.parkinsons.org.uk/PDF/Englandnursereport.pdf
16 Parkinson's UK (2011) Parkinson's nurses in Scotland- providing safe, effective and patient-centred care.
http://www.parkinsons.org.uk/PDF/Scotlandnursereport.pdf

[2] Mynors G, Perman S and Morse M (2012) *Defining the value of MS specialist nurses*. Multiple Sclerosis Trust. http://www.mstrust.org.uk/downloads/defining-the-value-of-ms-specialist-nurses-2012.pdf

[3] http://www.rcn.org.uk/Specialistnurses.pdf

skills and experience in the NHS with 3,994 fewer full time equivalent (FTE) nursing staff working in senior positions (bands 7 and 8). The staff affected by this includes ward sisters, community matrons, clinical nurse specialists and advanced nurse practitioners. A similar study has not yet been undertaken in Wales but we have evidence from our members that specialist posts have been under threat.

12. The RCN recommends that every patient with cancer should have the right to specialist nursing care, and ask that the Welsh Government undertake an audit of the number and type of cancer specialist nurses in Wales. Specialist nurse posts should also be supported through robust long term funding and time should be given to specialist nurses to ensure that they can fulfill the core elements of their role, namely providing clinical expertise, leadership and education and training.

13. At the Cross Party Group on Nursing and Midwifery in October 2013 we also discussed how we currently don't have the right follow up care in Wales. The system that we have in place currently is based on people's experience of cancer many years ago, not on how people experience cancer today. At least one in four people living with and beyond cancer – over 30,000 in Wales[5] - experience a wide range of long-term debilitating health conditions caused by their cancer or its treatment. This growing population of individuals with chronic health conditions will challenge existing care models and will need the ongoing support of practice and community nurses.

14. Nurses in the community are committed to meet the coming challenges but, historically, they have simply not benefited from the national vision and investment needed to provide us with the workforce we need today. Across the UK 27 per cent of NHS community nurses are over 50 and will have retired within the next 10 years. We are simply not educating enough new staff to fill these posts, let alone increase services. The RCN believes strongly that a renewed investment in the community nursing workforce is essential to support the changing nature on the way in which we provide health services in Wales.

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[4] http://www.rcn.org.uk/__data/assets/pdf_file/0007/564739/004598.pdf

[5] Macmillan estimate based on known cancer prevalence (Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 107: 1195-1202) and expert consensus, see Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*.

Royal College of Physicians | Coleg Brenhinol y Meddygon (Cymru)

National Assembly for Wales
[Health and Social Care Committee]

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan]

Evidence from Royal College of Physicians Wales – CDP 08

Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

RCP (Wales) consultation response

About us

The Royal College of Physicians (Wales) plays a leading role in the delivery of high quality patient care by setting standards of medical practice and promoting clinical excellence. We provide physicians across the world with education, training and support throughout their careers. As an independent body representing more than 29,000 fellows and members worldwide, including 1,000 in Wales, we advise and work with government, the public, patients and other professions to improve health and healthcare.

Amdanom ni

Mae Coleg Brenhinol y Meddygon (Cymru) yn arwain y ffordd o ran darparu gofal o ansawdd uchel i gleifion drwy osod safonau ar gyfer arferion meddygol a hybu rhagoriaeth glinigol. Rydym yn darparu addysg, hyfforddiant a chefnogaeth i feddygon ledled y byd drwy gydol eu gyrfa. Fel corff annibynnol sy'n cynrychioli mwy na 29,000 o gymrodorion ac aelodau ym mhedwar ban byd, gan gynnwys 1,000 yng Nghymu, rydym yn cynghori ac yn gweithio gyda'r llywodraeth, y cyhoedd, cleifion, a gweithwyr proffesiynol eraill i wella iechyd a gofal iechyd.

For more information, please contact:

Lowri Jackson
Senior policy adviser for Wales

Royal College of Physicians (Wales)
Regus House - Tŷ Regus, Falcon Drive
Cardiff - Caerdydd CF10 4RU

www.rcplondon.ac.uk/wales

Committee Clerk
Health and Social Care Committee
National Assembly for Wales
Cardiff CF99 1NA

HSCCommittee@wales.gov.uk

From the RCP vice president for Wales
O'r is-lywydd yr RCP dros Gymru
Dr Alan Rees MD FRCP

From the RCP registrar
O'r cofrestrydd yr RCP
Dr Andrew Goddard FRCP

Friday 04 April 2014

Dear committee,

Thank you for the opportunity to respond to your inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan. We would also like to thank the Association of Cancer Physicians for their help in drawing up this response.

The Royal College of Physicians (RCP) represents doctors in Wales and across the world working medical oncology, that is, physicians trained in the management of cancer. Their main area of expertise is in the systemic or drug treatment of cancer using chemotherapy, hormonal therapy and, increasingly, new molecular targeted therapy. Medical oncology also has a strong research basis: most medical oncologists are involved in clinical trials and many will have an academic post.

Overview

1. The RCP strongly welcomes the improvements outlined in the recent Cancer Delivery Plan annual report for 2013, especially improved survival rates at 14 per cent for one year, and 15 per cent for five year survival, with Wales showing the greatest increase of all four UK nations in recent years. However, there is still a great deal more to be done and cancer survival in Wales remains lower than the European average for most common cancers. Below we have outlined some of the areas from the cancer delivery plan itself which still need further work.

2. On **preventing cancer**, our physicians told us that there had been patchy developments made by local health boards. The overall activity was not overarching or strategic, and not enough work was being done through networks. However, there were some good local examples of best practice. On **detecting cancer quickly**, our physicians highlighted some capacity and compliance issues for bowel cancer screening at local health board level. Furthermore, we found that on **early diagnosis**, local health boards had made very little progress, with physicians reporting poor data and information, poor development of primary care oncology, and poor collaboration between primary and secondary care.

3. On **delivering fast, effective treatment and care**, we found that local health boards had made only patchy progress. There were some improvements in some areas, but physicians felt that there had been a lack of strategic planning and delivery for cancer treatment by health boards.

4. On **meeting people's needs**, our fellows and members told us that there was very little clarity over policy and strategic planning by local health boards in this area. There was little to no policy on key workers and care planning, and there was huge variation in follow up. Furthermore, our

physicians judged that Public Health Wales had provided poor support to local health boards to meet the information needs of people affected by cancer.

5. On **improving information**, our physicians reported ‘frustratingly little progress’ by local health boards. They described the progress made by health boards and trusts on data and information, ‘patchy at best’, and found that Public Health Wales and Velindre NHS Trusts (along with NWIS) had made little progress with providing a cancer clinical information infrastructure, or analysing local health board participation in clinical audit and peer review. Finally, **on targeting research**, they did report some positive work, but argued that this was actually being led by NISCHR, not the health boards or trusts.

Our response to the inquiry terms of reference

6. The Cancer Delivery Plan was published in June 2012. This means that any changes made are highly unlikely to have had sufficient time to be reflected in any of the outcome indicators, so it is very difficult objectively to assess progress. On the terms of reference for the inquiry, it is difficult, if not impossible to answer some of these, either due to short timescales or because of a lack of objective data.

Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016

7. Latest cancer official **Welsh Government figures on cancer waiting times** show that the 2016 target of 98% of patients starting treatment within 31-days of diagnosis, not via the urgent route, is already being met consistently. Although the target of 95% patients diagnosed via the urgent suspected cancer route, and starting definitive treatment within 62 days of GP referral, has not been attained in any quarter since publication of the cancer delivery plan, data for the latest quarter reached 92%, suggesting progress towards the target, though it is disappointing that only one of 6 LHBs achieved the 95% target.

8. We are not aware of any publicly-available statistics on stage-specific data so it is hard to make a worthwhile comment. However, it seems unlikely that there will have been any statistically meaningful downward stage migration in the time since publication of the delivery plan.

9. Wales Cancer Research Network figures from September 2013 show that both the 10% and 7.5% targets for cancer trials are already being exceeded in breast and haematological malignancies. Trials in urological cancers are meeting the 10% target, but not the 7.5% interventional target. In colo-rectal cancer trials, the 10% figure is being met overall, though not in two of the three regions of Wales, whilst the 7.5% interventional target is not being met in any of the three. The situation is very similar for lung cancer studies, except that only one of the three regions is not meeting the 10% target. It is disappointing that the details of monitoring of 30-day mortality following chemotherapy and surgery were absent from annex 3 of the cancer delivery plan and we could find no publicly available progress data on these key indicators. We could not find any collated figures, nor trends in the individual tumour types, but overall, there seems to be good, if inconsistent progress, across the main cancer types.

10. In the cancer delivery plan, the Wales Cancer Bank was identified as a ‘key research facility’. It has played a key role in the success of Cancer Research UK’s Stratified Medicine, and is fundamental to continuing to build on Wales’ leading role within stratified medicine in the UK. There was an increase in people diagnosed with cancer agreeing to donate to the Wales Cancer Bank – from 7.2% in 2011 to 10.6% in 2012 – so it is clear that progress is being made towards the target of 20%. However, this is an ambitious number, and we are not convinced that current rates will double by 2016 to meet this target.

11. Furthermore, while this progress has so far been achieved by dedicated research staff, we suggest that achieving the 20% target will require either additional funding and/or a different mechanism for obtaining consent eg introducing an ‘opt out’ approach of assumed consent to tissue donation for research, or the use of specifically-trained lay consenters.

Progress made in reducing the inequalities gap in cancer incidence and mortality rates

12. This is impossible to assess at this stage. As it is less than two years since the publication of the plan, any changes made have not had enough time to be reflected in any outcome measures. However, cancer service provision is an important determinant of mortality. There have been recent concerns regarding inequality in the provision of medical oncology services for the population of west Wales, and therefore the proposed incorporation of the provision of services for west Wales with Abertawe Bro Morgannwg University Health Board is a welcome prospect which should reduce the inequalities gap.

The effectiveness of cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups

13. We could not find any publicly-available data for the period beyond the publication of the Cancer Delivery Plan. The most recent update of the NSAG for cancer, published in January 2014, contains only data to the end of the 2011/12 period. It would be interesting to know whether figures are available for the take-up of anti-HPV cervical cancer vaccine.

Whether patients across Wales can access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner

14. We are not aware of any systematic barriers to accessing any aspect of cancer services in Wales, aside from expensive novel therapies (see below). We were unable to obtain any official statistics to comment on whether there are inequalities between health boards.

The level of collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams

15. The work of the third sector (including Tenovus, Cancer Research, Macmillan and Marie Curie Cancer Care) with cancer facilities (such as the Wales Cancer Trials Unit, Wales Cancer Bank and Cardiff Experimental Cancer Medicine Centre) has been crucial in making progress on the cancer delivery plan. The all-Wales Cancer Patient Experience Survey in January 2014 showed very high levels of scores of ‘excellent’ or ‘very good’, across the range of services, which suggests a good level of patient-centred care. However, we do have some concerns around the rarer cancers, survivorship issues and disparities between health boards.

Further points to note

16. There is much that is excellent about cancer care in Wales and good progress is being made on a number of fronts. However, we would like to highlight some areas of concern. In particular:

The lack of a Welsh Cancer Drugs Fund

17. Concerns have been raised that inequalities in access to effective novel therapies in Wales may have resulted from the creation of a cancer drugs fund in England since 2010, but not in Wales. The alternative system for accessing in Wales (Individual Patient Funding Requests) is a source of frustration to oncologists in Wales, and our physicians report that it is inconsistently applied by

local health boards. Our physicians asked us to highlight the case of the drug Bevacizumab for patients with ovarian cancer in Wales. In north and south east Wales, the only option for funding is to apply via the IPFR route. Unfortunately, all requests have so far been rejected by these health boards, despite it being widely used throughout Europe and England, and indeed, in south west and west Wales.

Phase I trials

18. In the absence of a cancer drugs fund, Phase I trials are an even more important means for patients to access novel therapies. However, it is disappointing not to have seen any specific mention of Phase I trials of new systemic anti-cancer therapies in the cancer delivery plan. Increasingly, trials are available through Velindre Cancer Centre and UHW, but the numbers are still disproportionately small, relative to comparable major population centres in the UK and to the excellent record of later-phase clinical trials activity in Wales. Phase I cancer trials activity in Wales should be a target for growth, yet there is no specific commitment of public funding for clinical service or clinical research in Phase I cancer trials.

Information technology

19. Accurate, accessible clinical information is crucial to both high quality clinical care and to forefront clinical research. However, the CaNISC electronic record system has failed to keep pace with comparable systems in the UK, and is significantly compromised by being far from universally used in cancer units in Wales. So far, there is no clear evidence that the development of an all-Wales cancer data warehouse has been able to facilitate either research or routine clinical practice.

Acute oncology

20. The provision of acute oncology services is very patchy in Wales and local provision is still almost non-existent in more than one of the larger health boards. There is clearly a long way to go to catch up with equivalent services in England and this must be a target for accelerated progress before 2016.

With best wishes,

Alan Rees

Dr Alan Rees
RCP vice president for Wales
Is-lywydd yr RCP dros Gymru

Dr Andrew Goddard
RCP registrar
Cofrestrydd yr RCP

National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Standing Welsh Committee of the Royal College of Radiologists – CDP 33

2 April 2014

Committee Clerk
Health and Social Care Committee
National Assembly for Wales
Cardiff Bay CF99 1NA

Dear Sir

Response of Royal College of Radiologists Standing Welsh Committee to the National Assembly for Wales' Health and Social Care Committee Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

The Standing Welsh Committee (SWC) of the Royal College of Radiologists represents the specialties of Clinical Radiology and Clinical Oncology within Wales. The majority of Oncologists and Radiologists working in Wales are Fellows of the College. We would make specific observations as follows, based on our consultation with colleagues in Wales.

1. The Standing Welsh Committee of the Royal College of Radiologists supports the aims of the Welsh Cancer Delivery Plan (CDP.) This sensibly takes a patient and population centred approach to the different stages of the Cancer Pathway. The aspirations are appropriate.
2. The importance of public health, early diagnosis, rehabilitation and survivorship, and the role of the third sector are recognised. Whilst there are clear targets for cancer management in secondary care, this is put into overall context rather than dominating. That is likely to be helpful in encouraging the production of integrated and balanced programmes.
3. The production by individual LHBs and NHS Trusts of their own local annual CDPs and Cancer Annual Reports (CAR) is, overall, felt to have been a useful exercise. It allows for tailoring and prioritising for local needs, which will vary. Existing programmes can be included into the larger delivery plans.
4. The CDP is ambitious, which is a good thing. It is multifaceted, and addresses some very complex problems. It is unlikely that all of the targets will be met by 2016. The health of populations is slow to change. Changes to hospital infrastructure and staffing take time. Some of the challenges are organisational, and some are

undoubtedly financial. The current financial climate will influence this, and a pragmatic and long term view is necessary.

5. Funds are mainly used effectively and probably give value for money. The current level of funding for cancer services in Wales is inadequate. There is inequity of access to appropriate treatments. Better funding may improve the efficiency of the CDP.

   There are disparities across Wales in ability to access certain treatments. A significant proportion of this is due to geographical location – for instance patients living further away from radiotherapy centres may choose to have non breast-conserving surgery, to avoid the 3 weeks radiotherapy. Whilst there is no easy solution, the perceived barriers to travel need to be broken down e.g. access to hostel accommodation, transport arrangements etc. The local MDTs need to ensure patients are fully aware of the reasons why some treatments may not be available locally.

   Non surgical oncology services need to be centralised and site specialised in order to ensure patients receive the highest quality care. This is not possible with the model of care in some DGHs with a sole oncologist treating all cancers. Health Boards need to ensure that cancer services are delivered in conjunction with the Cancer Centre, and that the guiding principles of ensuring treatment is given as close to home as possible is not done at the detriment of ensuring care is delivered by a site specialist team.

   The source of funding for “specialised cancer services” is not clear. There are different models of delivering “specialised cancer services” in Wales – with some services receiving WHSCC funding and others being funded through the LHB budget. At LHB level, the financial arrangements for provision of cancer care are opaque. It is thus impossible to know whether the amount spent for specialised cancer services per head of population is equal across Wales but we suspect not. There are disparities between Cancer Centres in terms of access to Clinical Nurse Specialists, Oncology Consultant numbers and radiographer numbers.

6. In Clinical Radiology, demand for diagnostic CT , MRI and ultrasound scanning currently outstrips capacity, as shown by longer waiting times for diagnostic tests in Wales compared with England. Access to PET scanning is commissioned at a lower level in Wales than in England.

   We have an aging population of consultant radiologists in Wales with considerable anticipated retirements in the coming years and there have been insufficient Welsh trainees coming through to replace them. Furthermore, the increasing number of cancer MDTs adds to the time pressures on radiologists, both in preparing for and attending these meetings. This makes it increasingly difficult to cope with workload. There is inequitable access to MRI scanning for suspected cord compression across Wales; at some hospitals, there are no formal arrangements for MRI radiographers to provide out of hours emergency MRI scans. There is no capitol replacement programme in some Welsh Health Boards for diagnostic equipment which can lead to aging imaging technology.

With kind regards,

Yours faithfully

Dr Richard Clements
Chair, Standing Welsh Committee
The Royal College of Radiologists

Agenda Item 4

National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Cancer Research UK – CDP 13

Cancer Research UK response to the National Assembly for Wales' Health and Social Care Committees inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

April 2014

Introduction

Cancer Research UK welcomed the introduction of the Cancer Delivery Plan and the creation of the Cancer Implementation Group in June 2012.

Cancer Research UK believes that cancer plans are essential in the fight against cancer . They set strategic direction and make the best use of resources to reduce cancer incidence and mortality. To continue to improve o make our cancer outcomes among the best in the world in the coming years, we need to maintain comprehensive cancer plans that incentivise action and dedicate resource to beating cancer.

We welcome the vision and priorities set out in the cancer plan. However we feel that more all Wales planning is needed, as there is currently variation in implementation of the plan by the different Local Health Boards. We therefore feel that the structures for delivering and implementing the cancer plan need to be strengthened, and we would like to see a more integrated all Wales approach.

We also feel that more could be done to better capture and analyse data in Wales to assess service delivery against the cancer plan, and to identify best practice.

The International Cancer Benchmarking Project (ICBP) has shown that UK cancer outcomes lag behind other comparable European Countries; evidence suggests this is due to both variation in access to treatment and late diagnosis, particularly the large number of cancers diagnosed through emergency admissions to hospital.

Our response therefore focuses on the action needed to diagnose cancers earlier in Wales, and to ensure people have equal access to the best treatment as recommended by their doctor.

These are the two areas that need to be prioritised if we are going to achieve better outcomes.

We have focused on: late stage cancer diagnosis in harder to reach groups; the variation in access to diagnostics tests in Wales; the effectiveness and take up of the bowel screening programme; and better access to treatments.

These are the areas where there is inequality, and where the cancer delivery plan lacks detail and national planning and oversight.

We would like to see:

Early diagnosis awareness campaigns considered at national level, and for local activity to be well coordinated, taking into consideration the needs of different population groups. This includes targeting lower socio-economic groups where indicated.

An improvement in the collection of staging data to ensure that we can identify and address problems with late diagnosis.

Better access to diagnostic tests for GPs

the Welsh Government develop a plan to add Bowel Scope Screening to the Welsh Bowel Screening Programme as soon as possible.

a data set for radiotherapy in Wales and a more joined up national comprehensive plan must be put in place for future service improvements

1.Early Diagnosis

Earlier diagnosis can dramatically improve survival for many cancers. For example, the ICBP has shown that when colon and colorectal cancer is diagnosed at the earliest stage, 1 year survival is over 90%, whereas when it is diagnosed at the latest stage survival is only 34%. [1]

The Welsh Government cancer delivery plan states that, "Local Health Boards need to raise awareness among public and health professionals about the risks and symptoms of cancer and how to act promptly and appropriately on this knowledge," and that "Diagnostic testing, particularly ultrasound and CT scans, should be available on request to primary care practitioners wherever this will reduce the time to diagnosis. All investigations that might demonstrate cancer should be reported promptly."

At the moment all of the LHB individual cancer delivery plans acknowledge the importance of diagnosing cancers earlier in Wales, and the need to plan campaigns similar to the 'Be Clear on Cancer Campaign.' Some LHBs specify details of how and what they are doing to achieve this. For example Cwm Taff has established a Community Cancer Awareness Network which brings together all cancer stakeholders, including primary care, to raise awareness of the signs and symptoms of cancer and to improve quicker diagnosis in primary care. Other LHBs state that they will plan future work but do not provide detailed plans.

We know that each year 5,600 patients in the UK are diagnosed with cancer at a late stage because of social and health inequalities 2. This is in part due to a lack of awareness of cancer symptoms amongst lower socioeconomic groups.

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[1] Maringe, C., *Stage at diagnosis and colorectal cancer survival in six high-income countries: A population-based study of patients diagnosed during 2000–2007.* Acta Oncologica, 2013. **52**(5): p. 919-932.

We would like to see awareness campaigns considered at national level and for local activity to be well coordinated, taking into consideration the needs of different population groups. This includes targeting lower socio-economic groups where indicated.

Analysis of accurate staging data across different cancer types plays a key role in gaining an understanding of where delays to diagnosis are significant. We acknowledge that recording and collection of staging data is improving in Wales and the Wales Cancer Intelligence and Surveillance Unit will be carrying out more work on staging data this year. However it will be important for the staging data to be analysed and priorities and actions set accordingly.

We would like to see an improvement in the collection of staging data to ensure that we can identify and address problems with late diagnosis.

Diagnosing Lung cancer earlier in Wales - Preliminary work by the Wales Cancer Intelligence and Surveillance Unit (WCISU) indicates that 51% of lung cancer patients had an emergency episode of care leading to their diagnosis.[3]

In October 2013, Cancer Research UK (CR-UK) hosted an all Wales Knowledge Sharing meeting on Early Diagnosis to discuss the early diagnosis of cancer and access to optimal treatments . The meeting looked at the latest data and the evidence base around current interventions to consider what work could be taken forward in Wales including data on cancer diagnosed through emergency routes. The group agreed that an early diagnosis initiative should be taken forward based on lung cancer covering information, workforce, campaigns and public information. We support a national initiative on early diagnosis in Wales and will continue to work with the Welsh Government to ensure that this activity is taken forward as soon as possible.

Access to Diagnostic tests – the need for better access to diagnostics tests to improve earlier diagnosis was also highlighted at the workshop. Experts were concerned about diagnostic test capacity, waiting times for tests, and the variation in access to diagnostic tests between localities and health boards. There was also concern that the current system is not equipped to take on the extra referrals that may be generated by future public awareness campaigns. It was acknowledged that preparing the system for any increased demand would need to be an integral part of any campaign s.

More needs to be done to ensure that GPs are aware of the availability of these tests, and that they are able to access them when requested. The Welsh Government will need to consider the level of funding needed to improve access to these tests.

2. Bowel Cancer screening

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[2] Lyratzopoulos, G. et al. Socio-demographic inequalities in stage of cancer diagnosis: evidence from patients with female breast, lung, colon, rectal, prostate, renal, bladder, melanoma, ovarian and endometrial cancer. Annals of Oncology doi:10.1093/annonc/mds526

[3] Presentation by the WCISU at CR-UK knowledge sharing working on early diagnosis. October 2013.

The Cancer Plan states that, “Screening services need to keep pace with the changing evidence of benefit and remain of the highest international standard. Action is needed to find more effective ways to increase take up by harder to reach groups.”

Survival rates for colorectal cancer patients in Wales are poorer than most other countries in Europe, [4]and older people and those from deprived areas are more likely to be diagnosed with cancer at a more advanced stage.

Improving overall uptake for bowel screening needs to be prioritised across all of Wales. Screening is the best way to diagnose bowel cancer early and early diagnosis is crucial - patients diagnosed with bowel cancer at the earliest stage have a better than 90% chance of surviving for five years, whilst for those diagnosed at the latest stage this drops to just 6.6%. [5]

We are currently piloting a campaign in North London, targeted at deprived communities, which aims to raise awareness, and remove barriers to bowel screening. We would be happy to share the results of this pilot in due course.

Cancer Research UK co-funded a 16 year study [6]which showed that Bowel Scope Screening (BSS) cuts deaths by over 40 per cent, and can actually prevent a third of bowel cancers among those screened[7]. The UK National Screening Committee has recommended Bowel Scope Screening (BSS) as an appropriate screening test for use in the UK’s screening programmes[8].

BSS is a one-off test at 55. It is an addition to the existing screening programme – people receiving BSS will still be invited to take part in the FOBT screening programme at 60. BSS is currently being piloted in six sites in England, with full coverage expected by 2016. The Scottish Government have also announced a two-year trial of BSS to start shortly.

We would like to see the Welsh Government develop a plan to add BSS to the Welsh Bowel Screening Programme as soon as possible.

Part of the plan should be an investment in endoscopy provision by the Welsh Government to ensure that services are equipped to take on bowel scope screening without impacting on other diagnostic and surveillance endoscopy services.

3. Equal access to treatment

The Cancer Plan states that, “Hospital services should be delivered promptly, be well co-ordinated with effective communication across boundaries and ensure good patient experience.”

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[4] Verdecchia, A., S. Francisci, and H. Brenner, *Recent cancer survival in Europe: a 2000-02 period analysis of EUROCARE-4 data (vol 8, pg 784, 2007).* Lancet Oncology, 2008. **9**(5): p. 416-416.

[5] http://www.cancerresearchuk.org/about-us/we-develop-policy/our-policy-on-early-diagnosis/our-policy-on-bowel-cancer-screening

[6] http://www.cancerresearchuk.org/cancer-info/news/archive/cancernews/2010-04-27-Five-minute-screening-test-could-prevent-thousands-of-bowel-cancers

[7] Atkin, W.S., et al., *Once-only flexible sigmoidoscopy screening in prevention of colorectal cancer: a multicentre randomised controlled trial.* Lancet, 2010. **375**(9726): p. 1624-33.

[8] UKNSC, *Note of the meeting held on 10 March 2011.* 2011.

However we feel that the commissioning and planning of treatment services, such as radiotherapy, could benefit from better national coordination and strategic planning.

Radiotherapy is a highly effective way of treating cancer. Four in ten people whose cancer is cured have received radiotherapy, and every year radiotherapy helps cure more people than cancer drugs.

New radiotherapy techniques like Intensity modulated radiotherapy IMRT are able to give precise doses to the tumour, rather than the surrounding tissue area.

However we know that the roll out of IMRT has been slow across Wales because of complex bureaucratic processes between the different Local Health Boards, and variation exists in access to advanced radiotherapy treatments. We believe that more national oversight could help address this.

We need a data set for radiotherapy in Wales and a more joined up national comprehensive plan must be put in place for future service improvements.

About Cancer Research UK

Every year around 300,000 people are diagnosed with cancer in the UK. Every year more than 150,000 people die from cancer. Cancer Research UK is the world’s largest cancer charity and is dedicated to saving lives through research. Together with our partners and supporters, Cancer Research UK's vision is to bring forward the day when all cancers are cured. We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. In 2012/13, we spent over £330 million on research in institutes, hospitals and universities across the UK. The charity’s pioneering work has been at the heart of the progress that has already seen survival rates in the UK double in the last forty years. We receive no government funding for our research.

In Wales fund the Wales Cancer Trials Unit which is dedicated to improving clinical practice through quality research evidence. We also fund the Cardiff Cancer Research UK Centre which draws together world class research and areas of medical expertise to provide the best possible results for cancer patients nationwide.

National Assembly for Wales

Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Macmillan Wales – CDP 16

Briefing for:	National Assembly Health and Social Care Committee.
Purpose:	Macmillan Wales response to the inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.
Contact:	Susan Morris, General Manager Wales.
Date created:	3rd April 2014

1. Introduction

Macmillan is committed to supporting partners, including the Welsh Government (WG), NHS Wales, Health Boards (HBs), Velindre NHS Trust and Local Government to improve care for people affected by cancer across Wales. We have invested nearly £10m in the last three years in improving cancer care in Wales and support more than 270 Macmillan professionals in Wales.

Macmillan welcomes this inquiry into the progress made to date on the implementation of the WG Cancer Delivery Plan (CDP) by the National Assembly for Wales' Health and Social Care Committee. We regard the WG CDP as a crucial lever for driving up standards, improving clinical outcomes and delivering the vision of person-centred cancer care in Wales. It is nearly two years since the WG launched its Cancer Delivery Plan and we believe that the Committee's inquiry is therefore timely and necessary to establish what progress has been made, where challenges exist and where the gaps are in its delivery.

Action is needed now if Wales is to achieve the vision set out in the WG Cancer Delivery Plan by 2016. We do not underestimate the scale of the challenge which requires committed and focussed clinical and managerial leadership at a national and local level.

With regards to the terms of reference for this inquiry, our response seeks to highlight:-

- whether Wales is on course to achieve the outcomes and performance measures, as set out in the CDP, by 2016; particularly in achieving the best in Europe ambition and improving outcomes in section 6.4 'Meeting People's Needs', a key area within the CDP for people affected by cancer.

- and whether progress has been made in reducing the inequalities gap in cancer incidence, survival and mortality rates.

2. Case for Change

As the diagnosis and treatment of cancer is becoming ever more effective, many more people are living longer with and beyond cancer. By 2030, it's estimated that the number of people living with or after cancer in Wales will nearly double to almost a quarter of a million (from 120,000 to 217,000) [i] As the nature of cancer changes, so do the needs of people who are affected by it – and the range of health and social care professionals and services required to help meet those needs. This growing population will have significant implications for both health and social care and will challenge existing models of cancer care. It is imperative that action is taken to ensure that care is holistic with non clinical needs routinely considered and covers social, financial, emotional, practical, psychological, spiritual and information needs. People need care beyond the clinical to enable them to live as well as possible and to become partners in their care enabling them to self manage as far as possible.

People who decades ago would have died shortly after diagnosis will increasingly survive for longer. 1 in 4 people will be living with the consequences and many will be living with an incurable cancer, remission and relapse. More focus is needed on this period of survivorship to improve quality of life, support patients to live well, as many more will be living with cancer, or the consequences of cancer as a long term condition.

3. Cancer Care in Wales

There are key policy documents, research and reports of patient experience which inform our response to the Health and Social Care Committee:

3.1 The *WG Cancer Delivery Plan* provides a national strategic approach to cancer treatment and care. It is the core document for steering cancer service delivery and monitoring cancer incidence, mortality and survival rates throughout Wales.

3.2 *The Cancer National Specialist Advisory Group: Technical Supplementary Report* collates epidemiological data, cancer specific profiles, audit and clinical trials and provides useful comparisons of data with other European countries. It therefore helps assess the progress made to achieving the ambition of being the best in Europe.

3.3 The *Wales Cancer Patient Experience Survey 2014* (CPES) results provide a robust and comprehensive analysis of people's experiences of cancer care in Wales, with the survey capturing the views of 7,352 patients and achieving a completion response rate of 69%. The CPES provides an important benchmark, both at a national and local level, in relation to the patient experience and the extent to which HB's are meeting people's needs as set out in the CDP*.* The survey was a joint initiative between Macmillan and Welsh Government.

It is important to acknowledge that the CPES results in January 2014 revealed high levels of satisfaction with NHS cancer care in Wales, with 89% of patients rating their overall care as excellent or very good and only 1% saying care was poor. This is a very clear indication that overall experience is a good one and provides a high baseline for further improvement. However, the survey results also show low compliance against the Cancer Delivery Plan commitments and significant variation in experience across Welsh hospitals, health boards and cancer types.

The recommendations made in this document are intended to boldly build on existing good practices and identify areas for improvement to aid progress towards achieving the ambition to be the best in Europe.

4. Key points for action

Macmillan is calling on WG to:

5.3 Provide clear strategic direction and leadership supported by an overarching all Wales structure for planning, accountability and performance. It should set priorities on an all Wales basis for a three year period until the end of 2016; set up robust monitoring systems to scrutinise and report openly on progress and use data to direct improvements in order to drive up standards and ensure a consistent approach to improving cancer care in Wales.

6.3 Review the content and quality of HB annual reports and ensure that HB Delivery Plans explicitly identify progress against <u>all</u> requirements within the Cancer Delivery Plan; ensure that HBs consistently publish their annual reports and delivery plans and ensure that they are timely, easy to access, clear and understandable. Proper overarching national scrutiny is needed to monitor standards, issue guidelines and ensure compliance against agreed targets.

6.6 Provide strategic leadership, absolute clarity and transparency on the application of waiting times, policies and targets and how performance against targets are measured. Action is needed now to ensure HBs achieve their waiting time targets so that patients do not face delays in being diagnosed or starting treatment.

6.9 Ensure HBs utilise the results of the Wales CPES data locally and explicitly demonstrate action taken to improve progress in delivering person centred care within their annual reports and delivery plans.

7.3 Produce a clear and unambiguous definition of the role of the Key Worker. This is crucial and urgently required to ensure equity of access and quality across Wales and will help ensure that the role is implemented consistently across HBs.

7.6 Produce a clear, nationally agreed definition of what the provision of holistic needs assessment and written care plan entails, linked with the role of the Key Worker, to help provide consistent equity of access and quality to person centred care across Wales.

7.9 Commit to ensuring that the recommendation within the Cancer Delivery Plan that people affected by cancer should have the opportunity to access welfare benefit advice is consistently implemented by HBs.

7.12 Develop an all Wales strategic quality assured approach to provide consistent, accessible and tailored information and support for cancer patients in Wales.

WG Together for Health – Cancer Delivery Plan

5. Responsibility and Accountability at a national level

5.1. The WG Cancer Delivery Plan should drive national change and improvement and thus ensure consistency in services and standards for patients throughout Wales. The Chief Executive of NHS Wales stated in the Foreword 'I will hold LHBs to account on the outcomes they deliver for their populations'.

5.2 **Macmillan Wales response:** The strategic direction of the WG CDP was much needed and hugely valuable in 2012 but its operational implementation, to date, has been limited. The standards and targets identified within the document now require further refining and monitoring needs to be strengthened. Furthermore, consequences of non compliance are not addressed due to lack of clarity in governance, self reporting and absence of any real levers that drive action and change. There is insufficient rigour in the current system to reduce variation and few opportunities to share good practice across teams and HBs and thus avoid duplication of effort. We welcomed the creation of the Cancer Implementation Group and the valuable progress it has made to date, however, in its current form it is unable to effectively bridge the gap between national policy and local implementation. Additionally, current arrangements and infrastructure do not allow national or cross health board network planning for initiatives such as acute oncology. There is a clear need to look strategically at these areas not just incrementally and at a local level.

5.3 Macmillan is calling on WG to provide clear strategic direction and leadership supported by an overarching national all Wales structure for planning, accountability and performance. It should set priorities on an all Wales basis for a three year period until the end of 2016; set up robust monitoring systems to scrutinise and report openly on progress and use data to direct improvements in order to drive up standards and ensure a consistent approach to improving cancer care in Wales.

A national all Wales approach would:-

- enhance current monitoring and support targeted intervention which would provide assurance that standards are being met;
- support effective use of resources and avoid duplication of effort;
- facilitate sharing and spread of good practice and learning;
- ensure action is taken to reduce variation and inequalities across health boards;
- improve co-ordination of care across complex care pathways between organisations;
- improve the delivery of integrated cancer care across primary, community and secondary care settings;
- create opportunities to review, challenge and decommission traditional care pathways which exist in a non-commissioning environment to ensure care is cost effective.

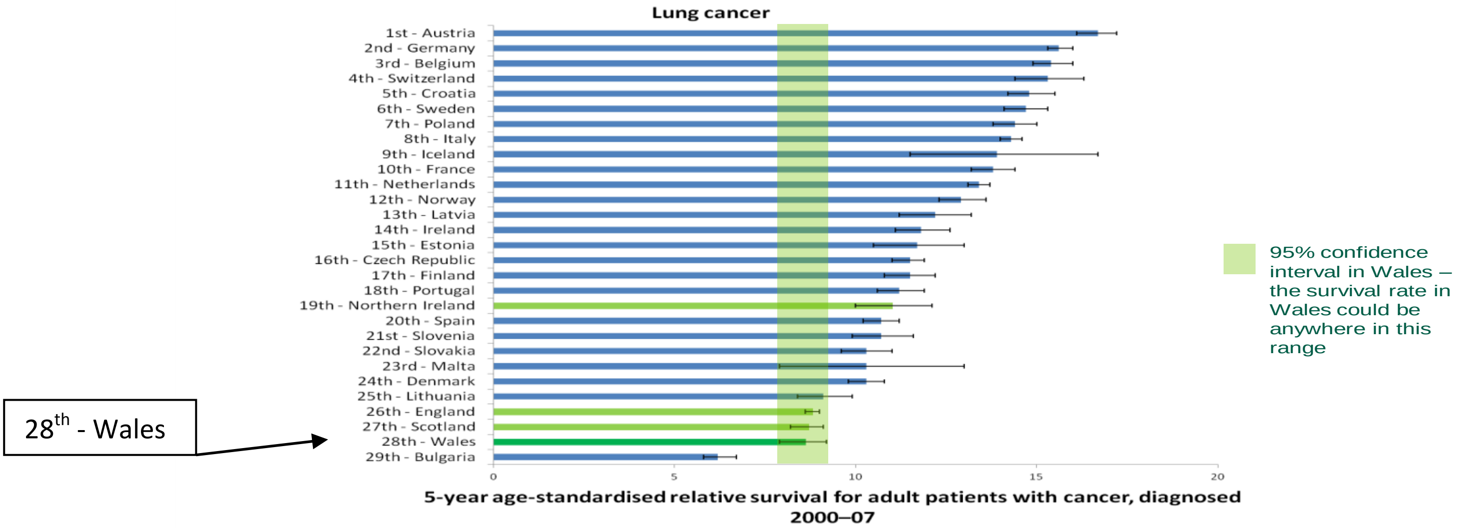
National outcomes

5.4 The WG Cancer Delivery Plan states that the *'NHS would work with ambition- locally, regionally and nationally- to make us amongst the best in Europe for cancer treatment and outcomes'*

5.5 **Macmillan Wales response:-** There is a need to keep pace with rapid change to ensure that cancer treatment is fast, effective and high quality. Whilst at a national level, five year survival in Wales has improved for stomach, rectal, breast and prostate cancers, there is minimal improvement in colon, lung and ovarian cancers. A Eurocare 5 population based study found that the UK and Republic of Ireland generally tend to have lower survival rates than the rest of Europe and report that the cancers where the UK and Republic of Ireland are most behind the rest of Europe are kidney, stomach and ovarian. A particular area of concern relates to lung cancer five year survival rates and the graph below (Figure 1) highlights very clearly Wales' position in Europe as 28th out of 29 countries and shows only one country, Bulgaria, as having a smaller survival rate than Wales. Evidence from the same source suggests that for other cancers Wales' position ranges from 19th out of 29 countries for Non Hodgkin lymphoma; 21st out of 29 countries for Breast and Prostate cancer. This demonstrates the huge challenge Wales faces in achieving the best in Europe ambition.

Figure 1.

Lung Cancer



De Angelis R, Sant M, Coleman MP, et al. Cancer survival in Europe 1999–2007 by country and age: results of EUROCARE-5—a population-based study. Lancet Oncol 2013; published online Dec 5. http://dx.doi.org/10.1016/S1470-2045(13)70546-1.

5.6 Compliance with NICE Improving Outcome Guidance and Wales National Cancer Standards are vital in delivering high quality cancer care. The Health Inspectorate Wales (HIW) Peer Review of cancer tumour sites is a significant and important development for Wales. It is essential that the evidence on performance is co-ordinated to measure how well Wales performs in terms of achieving national standards and that there is a coherent approach to ensuring that improvements are supported.

Information to date suggests that services and standards for rarer cancers, children, teenagers, older people and those living in deprived areas need to improve. **A national all Wales planning process which identifies priorities both one year ahead and until the end of the Plan in 2016, in line with the shift to three year financial planning for HBs, would improve and support strategic**

shifts and the radical change needed to move Wales closer to the aim of being among the best in Europe, as well as monitoring standards and compliance. A reliable and robust quality assurance system will assure everyone that Wales is progressing towards the ambition of being the best in Europe, make the gap transparent whilst measuring progress towards closing it.

6. Accountability and compliance at Health Board level

Reporting mechanisms

6.1 The WG Cancer Delivery Plan requires HBs to *"publish regular and easy to understand information about the effectiveness of their cancer services"* and *"publish an annual report on cancer services for the public of Wales each year to demonstrate progress"* and to *"produce and publish a detailed local cancer delivery plan to identify, monitor and evaluate action needed by when and by whom...and publish these reports on their websites quarterly."*

6.2 **Macmillan Wales response:** Our analysis of Health Board annual reports and delivery plans indicates that the implementation of these reporting commitments has only partially been met and that the quality of information about cancer services currently available to the public is patchy, inconsistent and inadequate. The quality and content of the published Reports is extremely variable and currently do not explicitly cover all the actions set out within the CDP. There is a lack of clarity within HB plans on how all the targets set in the CDP will be achieved by the date set of 2016. This is crucial to improving transparency, driving up standards, measuring outcomes and delivering person-centred cancer care consistently in Wales.

6.3 Macmillan is calling on WG to:- review the content and quality of HB annual reports and ensure that HB Delivery Plans explicitly identify progress against all requirements within the Cancer Delivery Plan; and that HBs consistently publish their annual reports and delivery plans and ensure that they are timely, easy to access, clear and understandable. Proper overarching national scrutiny is needed to monitor standards, issue guidelines and ensure compliance against agreed targets.

Achievement of waiting time targets

6.4 A key performance measure within the WG Cancer Delivery Plan is for HBs to meet the cancer waiting time 31 and 62 day targets.

6.5 **Macmillan Wales response:** Our analysis of cancer waiting times shows that HBs are generally meeting the 31 day requirement but for urgent suspected cases, the 62 day target continues to be missed, with over half of HBs missing the target every quarter for the last three years. The Welsh average for this target has not been met for nearly four years and presently stands at 92.1%. This is 2.9% below the target of 95%. Additionally, there appears to be some confusion and different interpretation over the start time of the 62 day target. Although some improvement has recently been reported this still means that between January 2013 to December 2013, 1,054 patients did not start treatment within the waiting time targets.[ii] The Wales CPES results also show that whilst 78% of patients felt they were seen as soon as necessary, 1,524 patients felt that they should have been seen sooner. We are aware that WG is currently reviewing its waiting time policy and targets.

Cancer patients must receive access to the right diagnostic tests and treatment promptly to give them the best chance of surviving and living longer with cancer. Macmillan has anecdotal evidence that patients in Wales are facing significant delays in accessing diagnostic tests and this is concerning. Unnecessary delays in diagnosis and starting treatment can cause significant distress and anxiety for patients, and their families, as well as adversely affecting their clinical outcomes and this must be addressed as a matter of urgency.

6.6 Macmillan is calling on WG to provide strategic leadership and absolute clarity and transparency on the application of waiting times, policies and targets and how performance against targets are measured. Action is needed now to ensure HBs achieve their waiting time targets so that patients do not face delays in being diagnosed or starting treatment.

Delivery of person centred care

6.7 The WG Cancer Delivery Plan makes a commitment to deliver person-centred cancer care in Wales and that '*people are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer'.* Specifically, it calls on HBs to a) assign a Key Worker; b) assess the clinical and non-clinical needs and provide patients with a written care plan and c) provide each GP with an "end of treatment" summary.

6.8 **Macmillan Wales response:** We understand that some of these commitments will take time to be fully implemented. However, we are concerned that there doesn't appear to be clear processes and structures in place to ensure consistent interpretation and delivery of these commitments across Wales. Delivering on these commitments and making person-centred care a reality requires HBs to do things differently. Our analysis of HB Delivery Plans reveals that crucial areas such as the implementation of a Key Worker, holistic assessment the actions from which provides patients with a personal written care plan are key to delivering person-centred cancer care, are not being consistently addressed across Wales. Furthermore, there is little evidence visible to demonstrate HB's commitment to undertake the planning and instigate the changes required to deliver on these commitments across Wales. Person centred care is not an optional extra it is crucial to delivering high quality care, reducing harm and can reduce inefficient use of limited NHS resources.

6.9 WG has committed to repeat the Wales CPES, possibly in 2015. The current survey results provide important baseline data and HB's need to act now in order to demonstrate future progress. Macmillan is calling on WG to ensure HBs utilise the results of the Wales CPES data locally and explicitly demonstrate action and the responses taken to deliver person centred care within their annual reports.

7. WG Together for Health – Cancer Delivery Plan: 6.4: Meeting Peoples Needs

Provision of Key Worker

7.1 The WG Cancer Delivery Plan includes a commitment that all people diagnosed with cancer in Wales will have a Key Worker assigned from the point of diagnosis onwards to co-ordinate their ongoing care.

7.2 **Macmillan Wales response:** Our analysis of HB Delivery Plans reveals there is mention of Key Workers but there is inconsistency in the interpretation and implementation of the Key Worker initiative in Wales. At present, the role and scope of the Key Worker role is defined and implemented locally, and we are concerned that this is leading to inconsistency in the way the role is implemented and geographical inequality in the quality of service provided for people affected by cancer in Wales.

The Wales CPES data provides evidence that not every individual with a diagnosis of cancer has a Key Worker and only 66% of the patients surveyed said they were given the name and contact details of their Key Worker. Results from individual HBs/Trust show that there are significant variations in the proportion of patients saying they were given the name of a Key Worker. Scores in HBs/ Trust ranged from 58% agreement at Hywel Dda uHB to 75% agreement at Aneurin Bevan uHB. Responses at Hospital site level reveal even more variation with only 49% of patients at Morriston and Glangwilli hospital reporting that they were given the name of a Key Worker compared with 74% of patients at Velindre hospital and Llandough hospital.

Macmillan's view is that during active treatment, a Clinical Nurse Specialist (CNS) should be appointed the Key Worker, responsible for co-ordinating treatment and care on behalf of a team of professionals caring for the patient, ensuring smooth transition and communication with the team, the patient and their families. When active treatment has finished, the Key Worker role, in most cases, should be transferred to primary care e.g. the GP, practice or community nurse as the main point of contact. The transition between secondary and primary care is often a difficult phase for patients and integrated care is essential to reduce patients feeling abandoned. A Key Worker is crucial in providing support or promotion of self care during this transition period.

Throughout the survey results, patients assigned a Key Worker consistently reported more positively on areas covering verbal and written information, involvement in their care, information on finances, discharge information, post discharge care and emotional support. There is overwhelming evidence within the Wales CPES that having a Clinical Nurse Specialist as a Key Worker enhances the delivery of cohesive care and provides an overall more positive experience for patients and their family throughout and beyond their treatment (Figure 2).

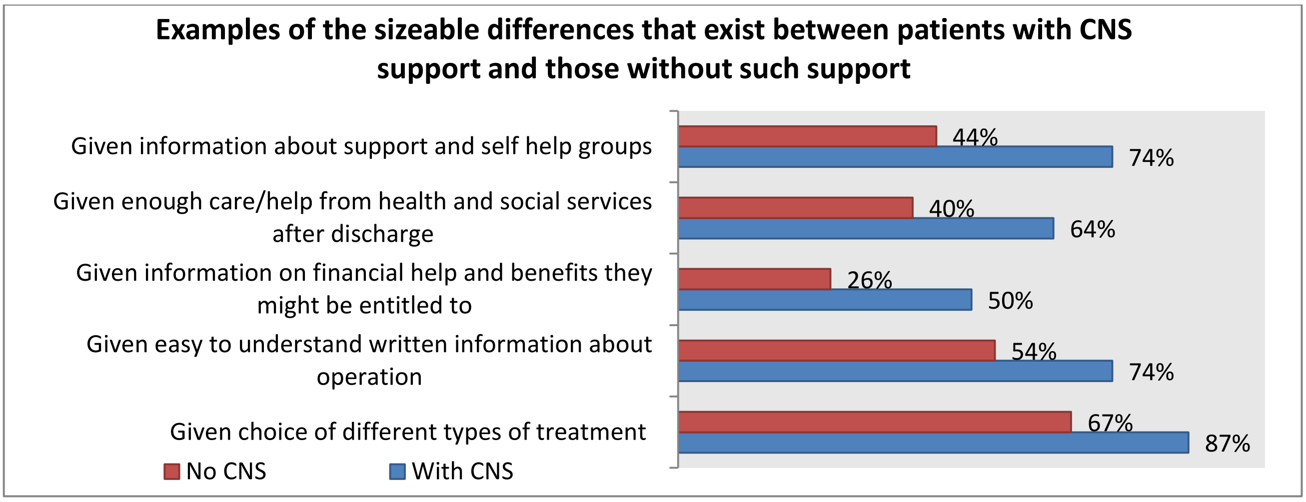


Figure 2: Wales CPES 2014.

"My key worker was the most important person on the planet during and after my treatment, she always clearly followed up what was said in clinic and still answers emails and chats on the phone even though I know she is so busy. Thank you". (Patient. Wales CPES 2014)

7.3 The WG Cancer Delivery Plan Performance measure required 100% of patients to be assigned a Key Worker by 2016. This performance measure has not been achieved yet. A clear and unambiguous definition of the role of the Key Worker is crucial and urgently required to ensure equity of access and quality across Wales and will help ensure that the role is implemented consistently across HBs.

Provision of Assessment and Care Planning

7.4 The WG Cancer Delivery Plan includes a commitment that all people diagnosed with cancer in Wales will receive an assessment of their clinical and non-clinical needs throughout and beyond their treatment with the outcome from this important discussion being written down in a care plan and a copy provided to them.

7.5 **Macmillan Wales response:** Our analysis of the HB Delivery Plans published reveal that all HBs, except Cwm Taf University Health Board, mention care plans. However, only Abertawe Bro Morgannwg University Health Board and Betsi Cadwaladr University Health Board mention holistic needs assessment. Despite this we are aware that many cancer patients in Wales are not being offered vital support in the months during, and after, their treatment to help them come to terms with their diagnosis, the side effects of treatment, its financial impact and preparing for care and self care after treatment. Appropriate assessment and care planning routinely implemented across Wales would help to ensure that this vital support is provided consistently across Wales.

Despite most HBs making reference to care plans, there is evidence within the Wales CPES results that shared decision making and care planning needs to significantly improve, with only 58% of patients highlighting that a discussion about their needs had taken place and only 22% of patients said they had been offered a written care plan. Furthermore, results from individual HBs / Trust show that there are significant variations in the proportion of patients saying they were offered the opportunity to discuss their needs and concerns and the proportion provided a written care plan. Scores in HBs/ Trust ranged from one in two (49%) agreement at Abertawe Bro Morgannwg uHB to two in three (67%) agreement at Velindre NHS Trust.

7.6 The WG Cancer Delivery Plan Performance measure required 100% of patients to receive a written care plan during and at end of treatment covering both clinical and non clinical needs by 2016. This performance indicator is unlikely to be achieved without significant and focussed effort and commitment by HBs. A clear, nationally agreed definition of what the provision of holistic needs assessment and written care plan entails, linked with the role of the Key Worker, to help provide consistent equity of access and quality to person centred care across Wales.

> *"After care needs to improve in my opinion as far as I'm concerned with more information and given written care plans laid out for people and as for key worker every time I rang it was always an answer machine so I gave up." (Patient. Wales CPES. 2014)*

Access to financial advice and support

7.7 The WG Cancer Delivery Plan includes a commitment for people affected by cancer to be "*routinely offered the opportunity to access financial advice and support as part of the care assessment and planning process".*

7.8 **Macmillan Wales response:** Macmillan has campaigned on this issue and we therefore warmly welcome this commitment; however, none of the HB Delivery Plans and Interim Reports make reference to how they address this requirement to ensure that all cancer patients are routinely offered the opportunity to access financial advice and support. Furthermore, there is clear evidence from the CPES data that it is not routinely being implemented across Wales. The CPES data highlights only 44% of patients said they had been given enough information about how to get financial help or benefits by hospital staff.[iii] Again significant variation exists at Health Board level and hospital site level as responses ranged from 22% of patients agreeing at Princess of Wales hospital and 60% at Wrexham Maelor Hospital.

Macmillan calculates that four out of five people affected by cancer in Wales are hit by the cost of a cancer diagnosis and on average are £640 a month worse off (£310 loss of income and £330 additional costs) During 2013 Macmillan Wales Welfare Benefit Advisers supported nearly 3000 people affected by cancer and obtained nearly £13.4 million in benefit income to help sustain them and their families during and after their cancer treatment.

7.9 The Macmillan Welfare Benefits service clearly highlights the importance of people affected by cancer being provided with benefit advice services and Macmillan Wales endorse the written evidence to the inquiry provided by Helen Powell, Macmillan Welfare Rights Service Redesign Project Lead, which provides further evidence and action required. Macmillan are calling on WG to reiterate their commitment to the recommendation within the CDP to ensure that people affected by cancer have the opportunity to access welfare benefit advice, if needed. An overarching all Wales national structure could support the delivery of a consistent benefit advice service to all people affected by cancer in Wales.

Provision of tailored information relating to cancer and treatment

7.10 The WG Cancer Delivery Plan included a commitment that '*people have access to timely information so they understand their condition and what to look out for and what to do and which service to access should problems occur*'.

7.11 **Macmillan Wales response:** Our analysis of HB Delivery Plans reveal that this area is very briefly covered and predominantly, tend to focus progress on the provision of clinical data and does not refer to meeting the information needs of people affected by cancer. High quality information and support is closely linked to a positive patient experience yet a number of the poorer scores given by patients in the Wales CPES data are in respect of information to them about key aspects of their condition, treatment and care. Again, there is variation of patient responses between the HBs and this is concerning.

> *The long and short terms effects of radiotherapy should have been explained fully in detail to me- allowing me to make an informed decision before proceeding. (Patient. Wales CPES. 2014)*

7.12 The importance of quality assured information and support for people affected by cancer has been substantiated in the written response to the inquiry produced by Caroline Walters, Macmillan/Public Health Wales Cancer Information Strategy Lead and highlights evidence and action required to take this important aspect of care forward. Macmillan are calling on WG to develop an all Wales strategic quality assured approach to provide consistent, accessible and tailored information and support for cancer patients in Wales.

8. Inequalities within population and cancer types

8.1 The WG Cancer Delivery Plan aims for Wales to have cancer incidence, mortality and survival rates comparable with the best in Europe and for the patient experience to be considered of equal importance as clinical effectiveness and patient safety.

8.2 **Macmillan response:** Our analysis of the CNSAG Technical Supplementary Report 2014 and the Wales CPES finds that inequalities within the population and cancer types exist in Wales.

Deprivation - We know that cancer has a greater impact in the more deprived areas of Wales. When responding to the Wales CPES patients in the most deprived groups answered less positively than those in the less deprived groups especially on questions relating to information needs, given easy to understand information about side effects, information about self help and support groups. This is a complex area and this group need additional consideration before, during and after their treatment. These results emphasise the importance of ensuring appropriate information is accessible to all groups in a variety of formats.

Tumour types/groups - In terms of responses from patients with different tumour types, patients with breast cancer were most likely to be positive about their care and treatment and the most likely to give poorer scores were patients with sarcoma, lung and urological cancers. The CPES data also suggests differences in experience between patients diagnosed with rarer and more common cancers.

General groups - The CPES results show that patients who commenced cancer treatment 5 years ago and over are less positive about their experience than those who started treatment in the last year. Patients who had other chronic conditions were also overall less positive about their experience. Furthermore, patients over 75 years old were not only less positive but appeared less likely to be assigned a Key Worker. Areas of concern surround arrangements for assessment and care planning, assignment of a Key Worker and provision of information for these groups.

This level of inequity of experience for different groups of people affected by cancer combined with the variation in delivery at each health board in Wales must be considered in more detail and focussed action taken to ensure improvements in these key areas are achieved.

8.3 A clear strategic direction and leadership supported by an overarching all Wales policy process and supporting structure for planning, accountability and performance would help reduce inequalities and ensure the commitments already made are delivered consistently for all groups of patients across Wales.

9. Conclusion

The WG Cancer Delivery Plan is an important framework and sets the direction and vision for cancer services in Wales. It enables us to look at a variety of measures in the delivery of high quality cancer treatment and care. Whilst some limited progress has been achieved in its implementation there is considerable work to be done to achieve the outcome indicators highlighted and the vision to be the best in Europe. There are significant gaps between the vision and targets identified within the document and the delivery and implementation across HBs in Wales. A lack of clarity and operational connectivity exacerbates the situation resulting in reduced accountability and transparency.

Person centred care is not an optional extra, it is core to delivering safe and effective and high quality care. Putting patients at the heart of cancer care is the solution to the increasing numbers of people needing care and the financial challenges facing the NHS in Wales. An overarching all Wales process and supporting structure for planning, accountability and performance, reducing the variation that exists between HB and hospital sites; decreasing the inequalities in the experience of patients with various tumour types and learning from the patient experience are crucial steps towards delivering the highest standard of care for everyone affected by cancer in Wales.

The Health and Social Care Committee Inquiry is timely and action by WG and HBs is needed urgently. WG and HBs need to refocus, provide bold leadership and increase the pace of change if real significant progress in implementing this ambitious plan and advance towards becoming the best in Europe, as set out in the WG Cancer Delivery Plan, is to be achieved by 2016.

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[i] Source: Internal analysis by Intelligence & Research, Corporate Development Directorate, based on figures from: Maddams J et al. (2008) Cancer prevalence in the United Kingdom: Estimates for 2008. British Journal of Cancer.

[ii] 822 patients not being treated *within the* urgent suspected cancer cases target and 232 patients non urgent suspected cancer waiting time.

[iii] All Wales Cancer Patient Experience Survey results 2014.

Figure 1. De Angelis R, Sant M, Coleman MP, et al. Cancer survival in Europe 1999–2007 by country and age: results of EUROCARE-5—a population-based study. Lancet Oncol 2013; published online Dec 5.

May 2014

Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

1 Follow up evidence from Marie Curie Cancer Care

1.1 Marie Curie Cancer Care welcomes the opportunity to provide further evidence to the Health and Social Care Committee regarding their inquiry into the progress made so far on implementing the Welsh Government's Cancer Delivery Plan.

1.2 Marie Curie provides hospice and community-based care and support to terminally ill people, their families and their carers in Wales and the rest of the UK. In the last year, just under three-quarters of the people our nursing service supported in the communities of Wales (about 1,300) and just under 90% (over 400) in our hospice had a cancer diagnosis.

1.3 Our initial response to the committee's inquiry focused on its first point of reference, 'Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016'. We raised concerns regarding progress towards delivery on two specific outcomes in the Cancer Delivery Plan. These are:

> Outcome 4 - *People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer*
>
> Outcome 5 - *People approaching the end of life feel well cared for and pain and symptom free*

1.4 Here we will expand on the points made previously and also discuss the inquiry's second point of reference, 'Progress made in reducing the inequalities gap in cancer incidence and mortality rates', based upon NHS statistics recently made available to us regarding cancer mortalities in the year 2012.

2 **Putting people with terminal cancer at the heart of care** (Outcome 4)

2.1 Under Outcome 4 in its summary of outcomes, the Cancer Delivery Plan stipulates that people have 'their individual needs identified and met' and 'patients and carers are involved in the design of services and people's views on services are sought regularly and acted on to ensure continuous improvement'. Section 6.5 of the Delivery Plan sets out that LHBs are to 'Support participation in cancer patient experience surveys, in particular the iWantGreatCare survey of palliative care patients and their families'.

2.2 Marie Curie believes that the current measures in place including the iWantGreatCare (iWGC) survey and use of patient concerns data is not sufficient to guarantee that the broad range of individual needs and views of people with cancer at the end of life across Wales can be identified and thus met. We have recently published a report, 'Listening to Dying People in Wales'[1], which explains why these measures alone and without refinement cannot go far enough (in line with the Welsh Government's 'Framework for Assuring Service User Experience'[2]) to ensure that service planning puts the needs and wishes of all people with terminal cancer at the heart of care.

2.3 Key messages from this report to note here include:

2.3.1 There are crucial points for analysis that are missed in iWGC data. For example, no information on the characteristics of the patient – such as their age, ethnic background, post code (by which the impact of socio-economic factors may be analysed using the Welsh Index of Multiple Deprivation) or type of cancer – is collected, and we know that all of these factors can influence the experience of care someone has at the end of life.

2.3.2 No information is collected on how well pain and symptoms were controlled in the final days of life.

2.3.3 The iWGC survey response rate is very low. Further to this, feedback is only collected from patients who are in receipt of care from a Specialist Palliative Care Team. Statistics show that less than half of those who died with cancer as the underlying cause in 2012 received any specialist palliative care. This means that over half of the people who died with cancer may not have had the opportunity to provide feedback on the care they received towards the end of life. For men who died from malignant neoplasms of the male genital organs (e.g. testicular cancer and prostate cancer) this figure is as low as 40%. Evidence also shows that the oldest patients are least likely to have received palliative care, therefore are least likely to have been asked for their thoughts on the care they did receive (see Appendix A for full information).

2.3.4 The feedback measures currently in place do not tell us about the coordination of end of life care services, such as how well the patient or patient's family felt the GP, District Nurse and Specialist Palliative Care Team worked together.

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[1] 'Listening to Dying People in Wales' (April 2014), Marie Curie http://www.mariecurie.org.uk/Global/Policy/Listening-to-dying-people-in-Wales.pdf

[2] 'Framework for Assuring Service User Experience' (April 2013), Welsh Government and NHS Wales http://www.wales.nhs.uk/sitesplus/documents/1064/Framework%20for%20Assuring%20Service%20User%20Experience%20-%20April%202013.pdf

2.4 The ability to understand needs and plan services so that they meet the outcomes set out in the Cancer Delivery Plan for those with terminal cancer requires that we know as much as possible about the patient, family and carer experience at the end of life. In 'Listening to Dying People in Wales', Marie Curie makes a series of recommendations. These include clearer guidance on the use of concerns data by Health Boards, and the introduction of an annual bereavement survey similar to the VOICES (Views of Informal Carers – Experience Survey) survey that is carried out in England. Without expanding sources of data to include such measures, it is difficult to see how individual needs will be identified and therefore met for a significant proportion of the people who die from cancer each year.

3 Ensuring people approaching the end of life feel well cared for and pain and symptom free (Outcome 5)

3.1 The following outcomes are included under Outcome 5 of the Cancer Delivery Plan:

- 3.1.1 More people receive palliative and end of life care and support on a 24/7 basis
- 3.1.2 People whose symptoms have not improved after 48 hours are referred to specialist palliative care
- 3.1.3 Less people being admitted unnecessarily to hospital

3.2 As stated above, statistics show that over half of people in Wales who died from cancer in 2012 did not (according to their medical records) receive specialist palliative care (see Appendix A). 3.1.1 and 3.1.2 will therefore require continued significant efforts if they are to be achieved. The focus on ensuring people at the end of their lives are on a Palliative Care Register (a key outcome indicator measure included in the Welsh Government's End of life Care Delivery Plan) should significantly improve this outcome. However, we are starting from a low (but fast improving) baseline. In 2009/10 3,721 people were on the Palliative Care Register rising to 7,152 in 2012/13. On the basis of estimated need this could still be as low as 25% of all those with a need for specialist palliative care. Some caution is needed in respect of these figures as there does not at present appear to be a direct read across between being recorded as being on a palliative Care Register and receiving specialist palliative care.

3.3 Regarding 3.13, statistics show that, in their final year of life, the 8,673 people who died with cancer as the underlying cause in 2012 were admitted to hospital over 21,000 times (please see Appendix B, 1a and 1b). Almost two thirds of these admissions were emergency rather than elective. On average, a person who died of cancer in 2012 spent almost 23 emergency days in hospital in their final year of life. When elective bed days are taken into account, the average number of bed days in the final year exceeds a month.

3.4 An emergency admission to hospital can be incredibly stressful for a dying person, and may well be clinically unnecessary. It is also very costly, not just financially, but in terms of the impact on the terminally ill person and their family. When pain and symptoms can be controlled and it is in line with their wishes, terminally ill people should be supported in the community as much as possible. There must also be adequate services in place to make sure that people who decide to remain at home are well cared for and pain and symptom free. Of the 46 Welsh GPs who responded to a recent survey commissioned by Marie Curie and Doctors.net.uk, only 40% felt that the majority of their patients being cared for at home in the final three months of life were completely free of pain all of the time. Less than a third felt that patients were able to get adequate access to care at night and weekends.

4 Progress made in reducing the inequalities gap in cancer incidence and mortality rates

4.1 The recent Public Health Wales Welsh Cancer Intelligence and Surveillance Unit's 'Cancer in Wales' report[3] found variations in cancer mortality rates dependent upon age, type of cancer, area of deprivation and across Health Boards. Point 2.3.3 above shows that factors such as age and type of cancer also correspond to variations in the likelihood of being referred to or in receipt of specialist palliative care for terminal cancer patients (please see Appendix A).

4.2 According to the 'Cancer in Wales' report, cancer mortality is over 50% higher in the most deprived areas of Wales. Data from the NHS Wales Informatics Service suggests that the journey through care for people who are dying with cancer in their final year may look quite different depending on similar factors. For example:

> 4.2.1 Admissions - There are variations in the balance between emergency and elective admissions depending on levels of deprivation (see Appendix B, 2A), with patients from the most deprived groups tending to undergo a higher number of emergency admissions whilst those from the least deprived have more elective admissions. A similar trend exists for deaths caused by cancers of the digestive and respiratory organs, which continue to be two major causes of death in Wales (Appendix B, 2B and 2C).
>
> 4.2.2 Bed days - For all deaths with cancer as an underlying cause and for malignant neoplasms of digestive organs, the average number of emergency bed days in the final year also increases in the final year as levels of deprivation increase. For digestive cancers, the average number of bed days is over 20% more for those in the most deprived group than for the least deprived (Appendix B, 3A and 3B – note only a very small upwards trend is found for malignant neoplasms of respiratory and intrathoracic organs).

4.3 Finding the narrative which explains these trends is a very difficult process which must go further than quantitative analysis. However, one possible route to explore may be that people with terminal cancer from the least deprived groups are more likely to have plans and supports in place which better facilitate their care within the community. Further work needs to be carried out to determine why these inequalities exist to ensure that any unjustifiable variations which exist in cancer care at the end of life are remedied.

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[3] 'Cancer in Wales' (April 2014), Public Health Wales
http://www.wcisu.wales.nhs.uk/sitesplus/documents/1111/CANCERinWALESapril2014FINAL%28Eng%29.pdf

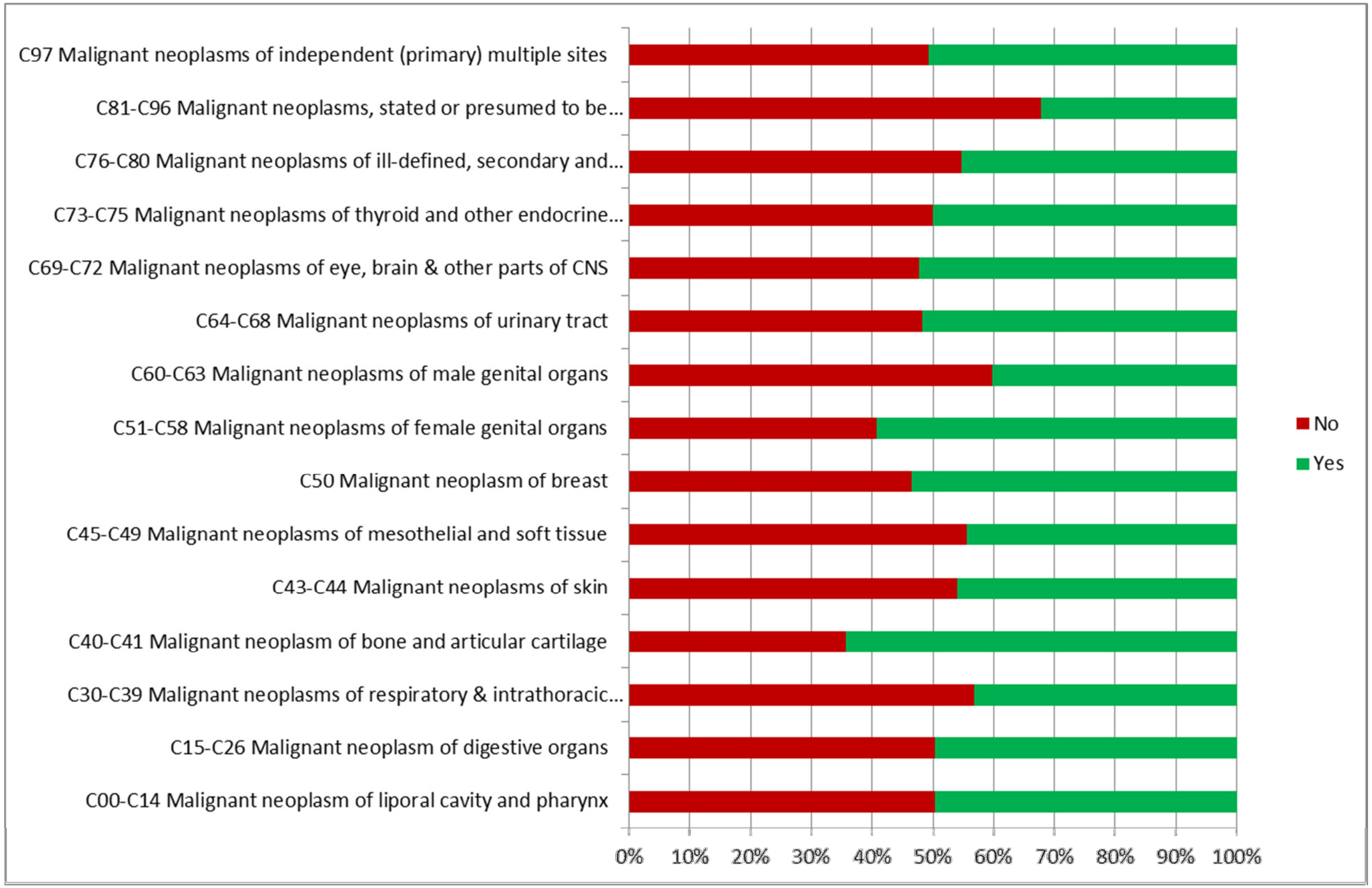
Marie Curie Follow-up Evidence for Health & Social Care Committee Inquiry into Progress made from Cancer Delivery Plan
May 2014

Appendix A: Palliative care inequalities

1 - Table showing variations in numbers of people receiving Specialist Palliative Care by underlying cause of death for all deaths from cancer in Wales, 2012:

	Recorded as palliative?			
Underlying cause of death – diagnosis subgroups	*No*	*Yes*	*Total deaths*	*% coded as palliative*
C00-C14 Malignant neoplasm of liporal cavity and pharynx	63	62	125	49.6
C15-C26 Malignant neoplasm of digestive organs	1267	1247	2514	49.6
C30-C39 Malignant neoplasms of respiratory & intrathoracic organs	1100	835	1935	43.2
C40-C41 Malignant neoplasm of bone and articular cartilage	5	9	14	64.3
C43-C44 Malignant neoplasms of skin	95	81	176	46.0
C45-C49 Malignant neoplasms of mesothelial and soft tissue	75	60	135	44.4
C50 Malignant neoplasm of breast	277	319	596	53.5
C51-C58 Malignant neoplasms of female genital organs	183	267	450	59.3
C60-C63 Malignant neoplasms of male genital organs	338	228	566	40.3
C64-C68 Malignant neoplasms of urinary tract	244	261	505	51.7
C69-C72 Malignant neoplasms of eye, brain & other parts of CNS	91	100	191	52.4
C73-C75 Malignant neoplasms of thyroid and other endocrine glands	13	13	26	50.0
C76-C80 Malignant neoplasms of ill-defined, secondary and unspecified sites	388	321	709	45.3
C81-C96 Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue	445	211	656	32.2
C97 Malignant neoplasms of independent (primary) multiple sites	37	38	75	50.7
Total/average	**4621**	**4052**	**8673**	**46.7**

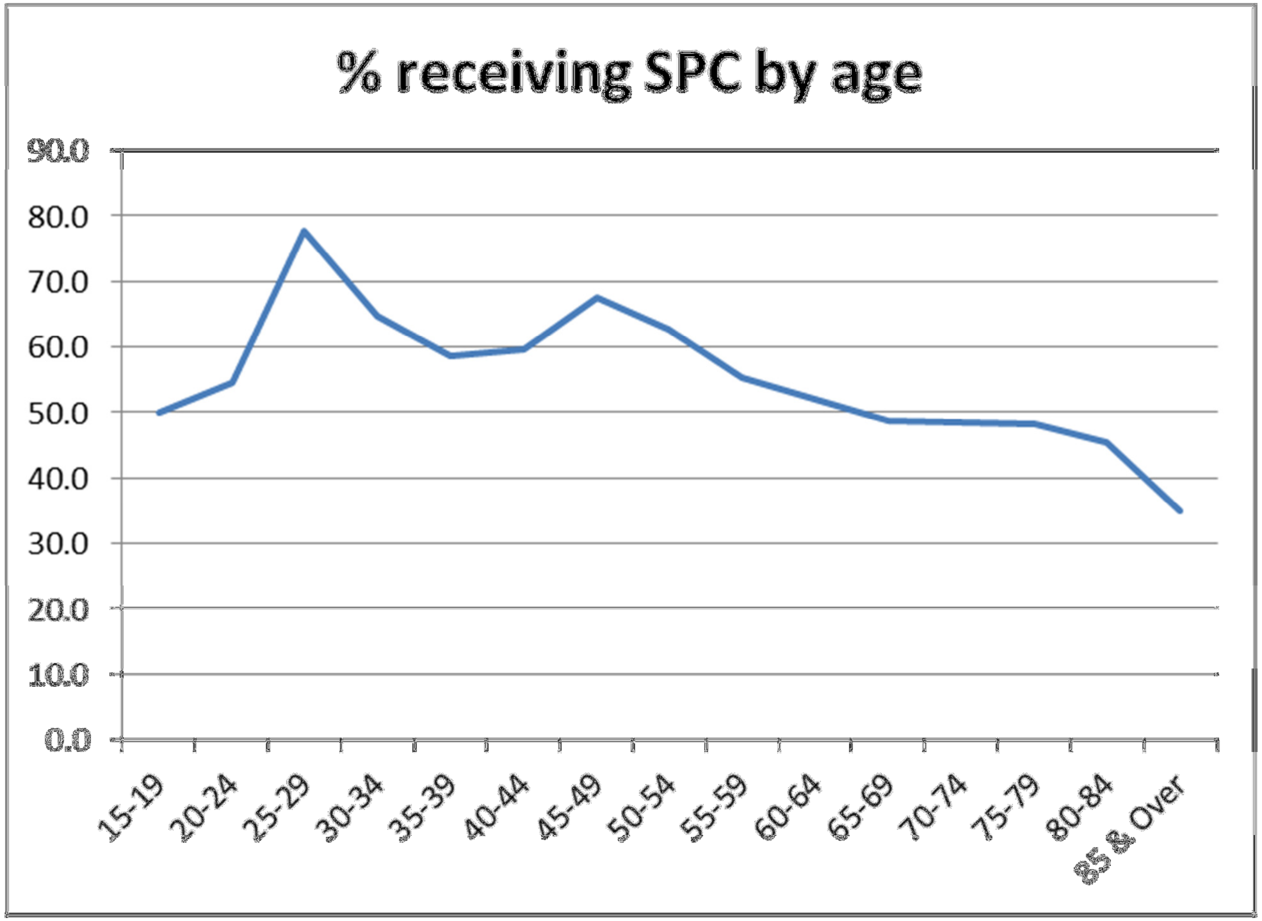
1b – Graph to show variations in numbers of people receiving Specialist Palliative Care by underlying cause of death for all deaths from cancer in Wales, 2012:



2a - Table showing variations in receiving Specialist Palliative Care by age group for all deaths from cancer of people in Wales aged over 15, 2012:

Sum of Deaths	Palliative			
Age group	No	Yes	Total deaths	% coded as palliative
15-19	2	2	4	50.0
20-24	5	6	11	54.5
25-29	2	7	9	77.8
30-34	6	11	17	64.7
35-39	17	24	41	58.5
40-44	33	49	82	59.8
45-49	50	104	154	67.5
50-54	93	156	249	62.7
55-59	180	223	403	55.3
60-64	349	380	729	52.1
65-69	538	509	1047	48.6
70-74	663	626	1289	48.6
75-79	717	666	1383	48.2
80-84	783	654	1437	45.5
85 & Over	1176	634	1810	35.0
Total/average	**4614**	**4051**	**8665**	**46.8**

2b - Graph showing trends in receiving Specialist Palliative Care by age group for all deaths from cancer of people in Wales aged over 15, 2012:



Appendix B: Admissions and bed days

1a. Tables to show admissions in the final year for all deaths with cancer as the underlying cause (C00-C97) in Wales in 2012:

Sum of Deaths	Emergency admissions	Elective admissions	Total admissions
8673	17532	9609	27141

% admissions that were emergency	% admissions that were elective
64.6	35.4

Emergency admissions per death	Elective admissions per death	Total admissions per death
2.0	1.1	3.1

1b. Tables to show bed days in the final year for all deaths with cancer as the underlying cause (C00-C97) in Wales in 2012:

Sum of Deaths	Emergency bed days	Elective bed days	Total bed days
8673	198830	77410	276240

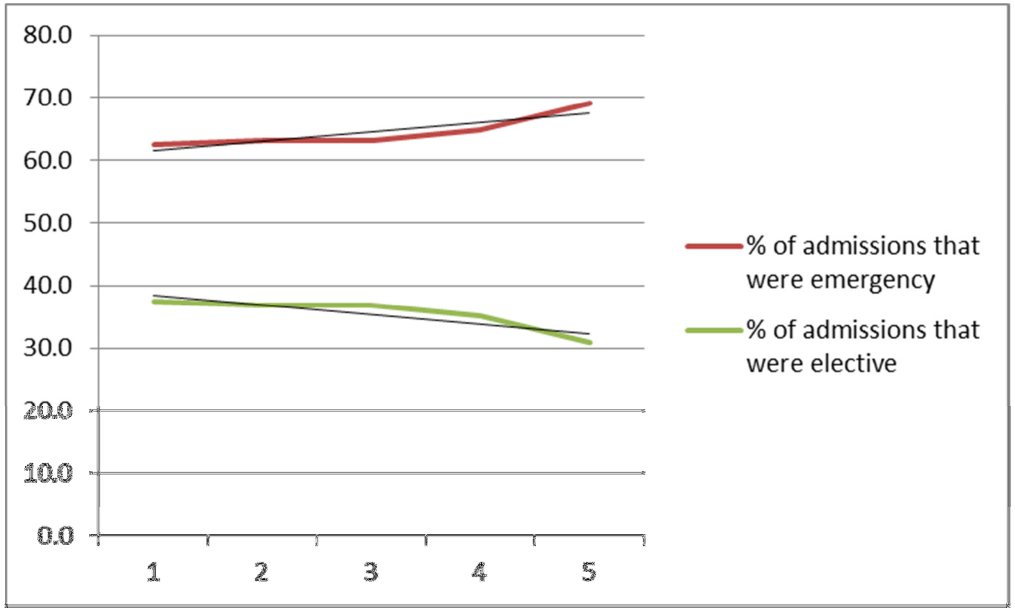
% bed days as an emergency	% bed days that were elective
72.0	28.0

Emergency bed days per death	Elective bed days per death	Total bed days per death
22.9	8.9	31.9

2. Balance between emergency and elective admissions in the final year of life broken down by deprivation quintiles (where 1 is the least deprived and 5 the most deprived) for:

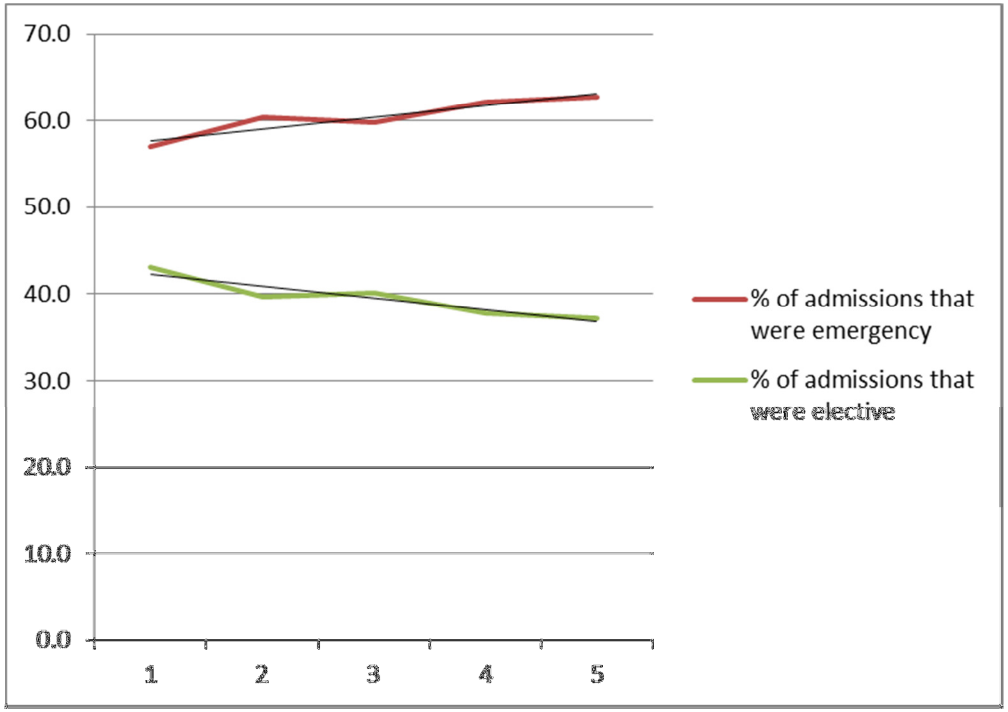
A. all deaths with cancer (C00-C97) as underlying cause, Wales 2012:

Deprivation quintile	% of admissions that were emergency	% of admissions that were elective
1	62.5	37.5
2	63.1	36.9
3	63.2	36.8
4	64.9	35.1
5	69.2	30.8
Average	64.6	35.4



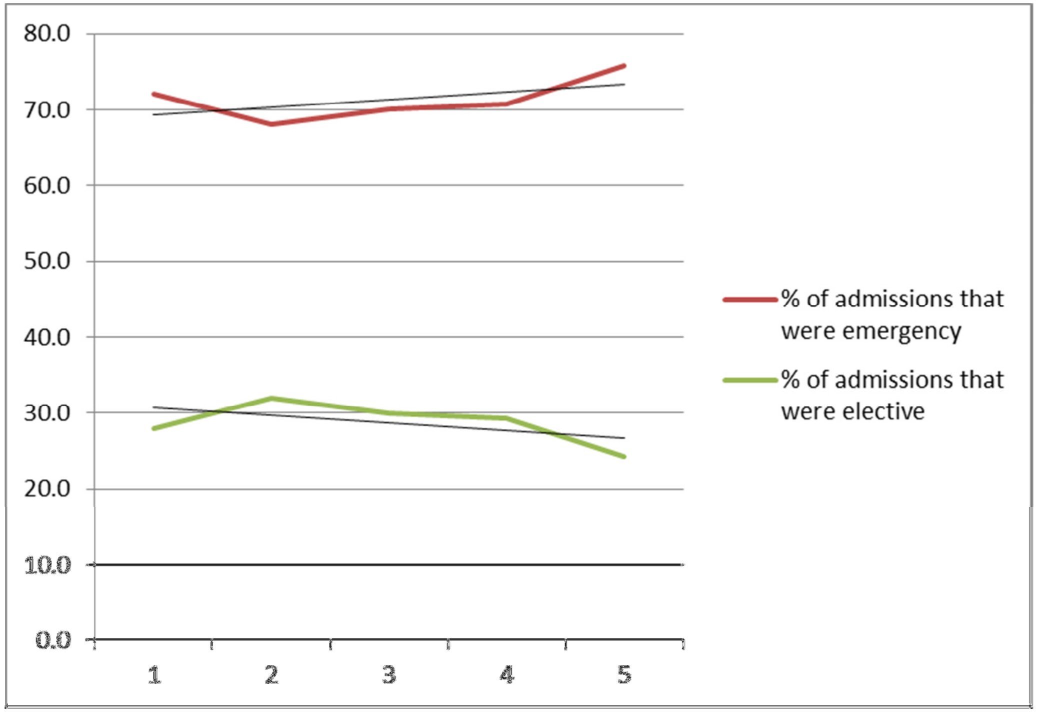
B. Malignant neoplasms of digestive organs as cause (C15-26):

Deprivation quintile	% of admissions that were emergency	% of admissions that were elective
1	56.9	43.1
2	60.4	39.6
3	59.8	40.2
4	62.3	37.7
5	62.8	37.2
Average	60.4	39.6



C. Malignant neoplasms of respiratory and intrathoracic organs as cause (C30-39):

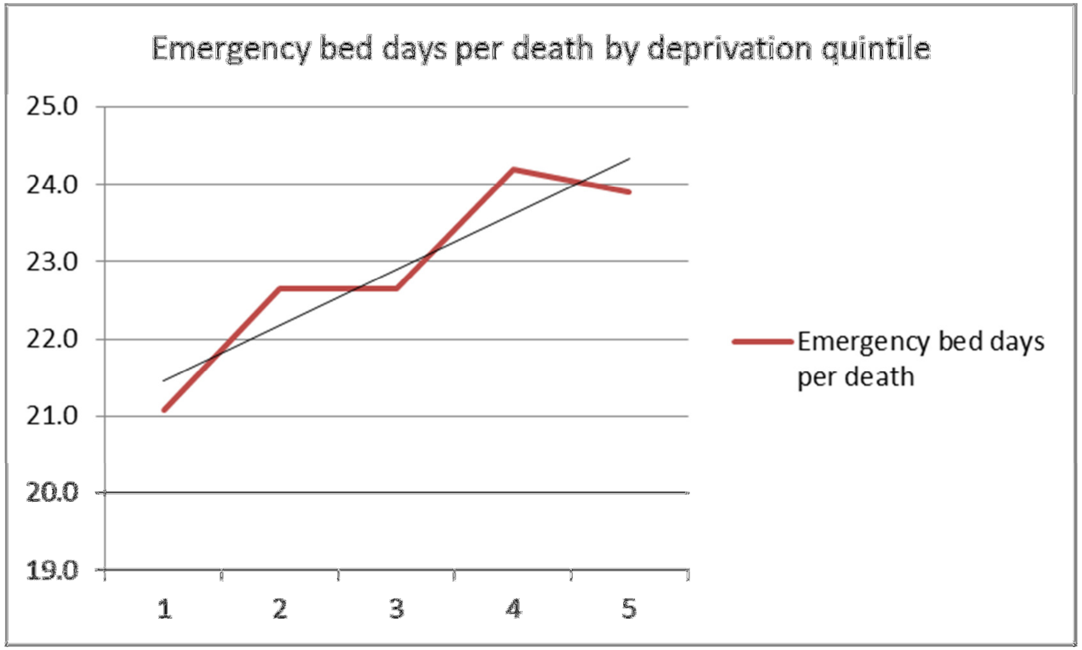
Deprivation quintile	% of admissions that were emergency	% of admissions that were elective
1	72.0	28.0
2	68.1	31.9
3	70.0	30.0
4	70.7	29.3
5	75.8	24.2
Average	71.6	28.4



3. Trends in emergency bed days in the final year of life by deprivation quintiles for:

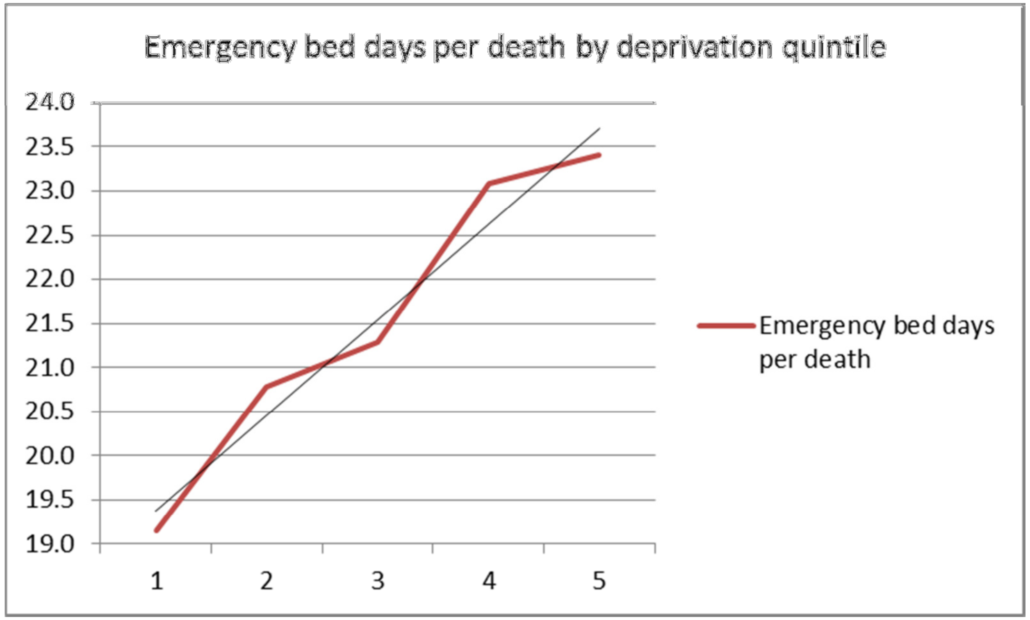
A. all deaths with cancer (C00-C97) as underlying cause, Wales 2012:

Deprivation quintile	Emergency bed days per death
1	21.1
2	22.6
3	22.6
4	24.2
5	23.9
Average	22.9



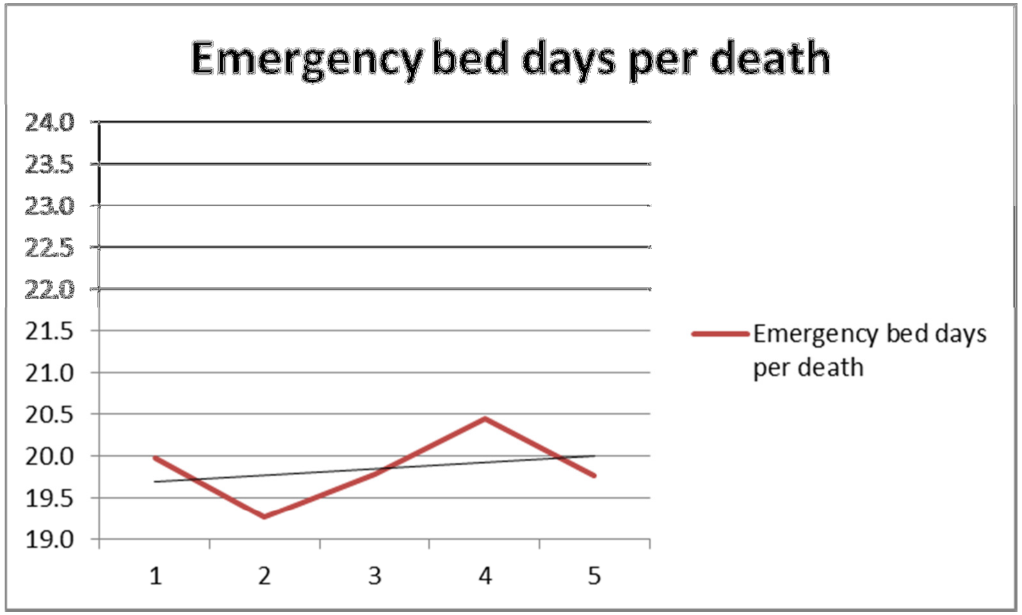
B. Malignant neoplasms of digestive organs as cause, Wales 2012 (C15-26):

Deprivation quintile	Emergency bed days per death
1	19.1
2	20.8
3	21.3
4	23.1
5	23.4
Average	21.5



C. Malignant neoplasms of respiratory and intrathoracic organs as cause (C30-39):

Deprivation quintile	Emergency bed days per death
1	20.0
2	19.3
3	19.8
4	20.4
5	19.8
Average	19.9



National Assembly for Wales

Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Tenovus – CDP 28

Tenovus response to the National Assembly for Wales' Health and Social Care Committees inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.

At Tenovus we want a future where fewer people develop cancer and everyone with cancer has equal access to excellent treatment and support. We offer support, advice and treatment for cancer patients, information on cancer prevention and funding for research to improve the outcomes for people with cancer. We do this where it is needed most - right at the heart of the community.

In 2012 Tenovus welcomed the introduction of the Cancer Delivery Plan and its vision to provide world class health care services to people affected by cancer in Wales. We were also pleased that patient centred care was seen as integral to achieving this aim and that many of the key priorities set out in the Plan matched our own strategic aims and objectives as a service provider to thousands of patients and families affected by cancer in Wales each year.

Below is our response to the progress of the Cancer Delivery Plan to date, focussing on the areas set out in the terms of reference as requested.

1. **Is Wales on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016?**

At this stage it is probably too early to tell if the Cancer Delivery Plan is having a positive effect and whether this will lead to the desired outcomes by 2016. Whilst the Wales Cancer Intelligence Surveillance Unit (WCISU) is an excellent resource for cancer statistics in Wales there needs to be a greater use of this data to drive improvements and identify areas of weakness as soon as they arise. This is symptomatic of a need for greater national planning and leadership in relation to cancer services in Wales.

Whilst the CIG was established to provide some of this oversight and strategic direction it does not have the resources or the authority to do so effectively. Tenovus would welcome a national planning structure with responsibility for better and more expedient data collection and analysis, advising LHBs where the performance gaps in services are shown to exist and delivering the aspects of the plan which require a systematic national focus and commitment.

This would provide clearer leadership and therefore accountability. It would also help us in Wales to plan for long term success that crosses LHB boundaries, with clear deadlines and targets against which progress can be measured.

2. **Has progress been made in reducing the inequalities gap in cancer incidence and mortality rates?**

Currently in Wales there are approximately 120,000 people who have experienced a diagnosis of cancer, and with around 50 more people diagnosed everyday this is set to double by 2030. In the last 15 years there has been a significant increase in the number of cases of cancer diagnosed each year, but thanks to continuing improvements in our ability to detect and treat cancer the numbers of people who actually lose their lives due to the disease has actually decreased.

However there are still great disparities which determine how likely you are to get cancer and how likely you are to recover from it. For example, in Wales, as in many countries, the poorer you are the more likely you are to develop cancer. In fact if you are a man and live in one of the most deprived areas of Wales you are up to 21% more likely to develop cancer than someone who lives in a more affluent area. If you are a woman you are around 14% more likely to develop cancer.

Even more shockingly, not only are you more likely to develop cancer if you are poor but you are also more likely to die from it compared to someone from a more affluent area. For example, for every 2 individuals who die of cancer in the most affluent group in Wales, 3 die in the poorest [1].

There are also some types of cancer where the outcomes for patients are far more likely to be worse than others. Probably the starkest example of this is lung cancer, a disease which has seen little improvement in survival rates over the last few decades and is today Wales' biggest cancer killer. However, we have made huge strides in successfully treating many other common cancers and improved survival rates dramatically. This has been achieved through a mix of increased public awareness, an established screening service and improvements in treatments and surgery, much of which has been demanded and driven by the patients themselves over a number of years.

We are pleased to see that both 1 year and 5 year survival rates from cancer have improved in Wales however these figures pre-date the implementation of the Cancer Delivery Plan and we may have to wait several years until the data is available to see if the Plan has helped drive these improvements even further.

Also, whilst these improvements are heartening, they are also far overdue and need to continue at a pace if we are to get anywhere near matching the best survival rates in Europe. For example survival rates for lung cancer are the 28th lowest in Europe out of 29 countries. We are also behind the European average in terms of survival for a number of other common cancers [2]. In fact if we just matched the best in Europe in terms of survival across all cancers we would save the lives of over 600 patients per year.

3. **The effectiveness of cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups.**

We know that early detection (and indeed detection of pre-cancerous conditions) through screening programmes has saved many lives. However we are concerned that the uptake of screening is not meeting national targets in Wales and that the uptake of screening varies greatly between different socioeconomic groups further driving the inequalities seen in incidence and survival described above.

For example, we know that women from more deprived areas are less likely to attend cervical and breast screening [3] and in Wales screening uptake varies hugely by area, for example, patterns of low uptake in breast screening closely match patterns of deprivation in Wales [4]. Despite this little research is being done into targeting socioeconomic groups with a low screening uptake. More funding for research in this area, in-line with the Welsh Government's emphasis on evidence-based policy-making and stronger links between research and policy e.g. through the Knowledge Exchange Trials programme, is essential not only for improving screening uptake but improving it among the socio-economic groups most likely to benefit.

Black Asian Minority Ethnic and Refugee (BAMER) groups and screening is a relatively unexplored area and the links between racial equality and health remain tenuous despite allusions by the Welsh Government to ensuring cultural inclusivity in health care (Ruth Hussey, All Wales Annual Race Equality Conference, 2014). This could be done through stronger links between Local Health Boards and community cohesion programmes within local authorities. In addition working in partnership with organisations such as Communities First and voluntary organisation in a systematic and structured way could improve screening uptake among hard to reach and minority groups.

Wales also has to keeps up with the latest developments in effective screening not just in the UK but also globally. Cervical Screening Wales has announced that they are planning to assess the impact of HPV triage on the screening programme in Wales and will make a recommendation to the Welsh assembly government on any potential plans to adopt HPV triage as a policy. This has already been adopted as common practice in England and should lead to less women being unnecessarily treated for suspected cervical cancer reducing harm to the individual and costs to the health service. If this is found to be the case then we are calling for the screening services to also adopt this as routine practice.

Low awareness and negative beliefs about cancer are likely to contribute to delayed presentation with cancer symptoms, leading to advanced stage at presentation and a smaller chance of survival. In 2011, researchers from Cardiff University's School of Medicine joined forces with Tenovus and the Welsh Government as part of the International Cancer Benchmarking Partnership (ICBP) the largest international research study designed to examine the root causes of international differences in cancer survival.

Through this study it was shown that Wales and the UK generally had an average knowledge of symptoms relating to cancer, but had a poor knowledge that increasing age was a risk factor and also had the highest level of perceived barriers to symptomatic presentation, in particular being worried about "wasting the doctor's time" [5].

4. Can patients across Wales access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner?

Once an individual is told that they have a suspected cancer, whether via a screening route or from GP referral, this is one of the most emotionally distressing times imaginable. The NHS in Wales has set the maximum wait for access to specified diagnostic tests at 8 weeks. However a recent report shows that overall the number of people waiting for diagnostics has increased dramatically over the past two years and as of January this year 41.6% of all people in Wales waiting for diagnostic endoscopy have waited for more than 8 weeks. This is alone represents 5,228 people waiting for a diagnosis relating to a bowel condition, some of which will include cancer [6].

As the population continues to age in Wales, awareness of cancer increases and screening services become more fully utilised, the need for diagnostic testing is going to greatly increase. Therefore much greater investment is needed in this area to ensure that individuals with cancer are treated expeditiously and those who don’t have cancer can have their fears alleviated.

There will always be for some specialist services to be centralised to ensure that the right level of expertise or facilities are available. However there are also a number of services that can be taken out into the community alleviating the pressure on already overcrowded waiting rooms whilst also reducing journey times for cancer patients and families at an already stressful time. Since 2009 Tenovus has helped to do this through our mobile chemotherapy and lymphoedema services in partnership with Local Health Boards in Wales.

Technology also provides us with new opportunities, not least telemedicine which can be used to for remote diagnosis, treatment and follow up and is already routinely used in other countries with rurality issues that dwarf ours (e.g. Canada, US, Australia). There have been a number of telemedicine pilots that have taken place in Wales in recent years including a project in Hywel Dda for head and neck cancer patients funded by Tenovus. However there needs to be a coordinated approach to this issue on an all Wales level that brings together the best expertise in Wales with models of global best practice to drive the use of this technology forward.

5. **Collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams.**

Tenovus has worked closely with the NHS in Wales over a number of years and shares the Cancer Delivery Plan’s vision of greater patient centred care and world class treatment, support and care for cancer patients in Wales.

Below are just some of the ways in which Tenovus is already helping to deliver this and some areas where we feel the NHS and third sector could work more closely to provide even greater care and support to a larger number of patients and their families.

Prevention- Over the past 3 years we have delivered more than 3500 cancer specific Health Checks to people in some of the poorest places in Wales. This has led to a partnership with Cardiff University which has secured £150,000 in funding from the National Awareness and Early Detection Initiative (NAEDI) to evaluate its effectiveness as an intervention for promoting healthy living and identification of common cancer symptoms in areas of high social deprivation.

Clinical Trials- Tenovus is currently funding a research project with NISCHR CRC which aims to improve the cancer patient experience of being introduced to research. As is highlighted in the Cancer Delivery Plan Annual Report, only 29% of patients had been asked about participation in research. We hope to use the findings of this study to increase research participation not only in clinical trials but also research that improves vital areas of care such as information provision, psychosocial support and the development of best practice in allied health care services.

Research- Tenovus is one of Wales' largest cancer research funders and will this year invest around £1m in research that covers the whole patient journey. We are also one of the biggest funders of PhD studentships in Wales which not only helps to increase research capacity and training in Wales but also provides some of the newest avenues for research and cutting edge discoveries.

Treatment closer to home- Since 2009 we have worked in partnership with Velindre to deliver chemotherapy in the community closer to where people live. In fact, our mobile units have delivered over 10,000 treatments to date and in 2012/13 saved cancer patients in Wales from traveling over 55,000 miles to and from hospital. Also, since January 2012 we have used our Mobile Units to provide a range of treatments for patients with lymphoedema. In October 2013 we launched our 2nd Mobile Unit which is set to deliver around 6500 treatments for patients affected by this debilitating condition all over Wales, the first mobile service of its kind in the UK.

Practical Advice and Emotional Support- Tenovus provides a wide range of services to cancer patients and their families and can support them from point of diagnosis right through to survivorship or end of life care. Whilst many positives came out of the recent Wales Cancer Patient Experience Survey [7] carried out by Macmillan and Welsh Government, we were greatly concerned that nearly 1 in 4 patients who would have liked information about emotional support, such as self-help groups, were not offered any information, and half of all patients who would have liked information about financial issues or benefits also did not receive any. This is an example of where the NHS and the third sector could coordinate much more effectively to provide support for cancer patients and families in Wales. The Tenovus Cancer Support Team provides a wide range of services for cancer patients including advice on money matters and benefits, counselling, a nurse led support line available 8am-8pm 7 days a week and a range of innovative and effective support groups such as the Tenovus Sing With Us Choir programme. In 2012 Tenovus received the Advice Quality Standard from the Legal Services Commission in recognition of the quality of our advice services.

We have also developed a proactive telephone support service called Tenovus Cancer Callback through a collaborative project between Tenovus, Velindre and the University of Glamorgan funded by the Burdett Trust for Nursing. The project began in April 2012 and allows Tenovus to implement a schedule of callbacks to any cancer patient in Wales undergoing treatment and to follow those patients up for at least 6 months.

6. **Whether the current level of funding for cancer services is appropriate, used effectively and provides value for money.**

With an ever increasing incidence of cancer and a health and social care system already creaking under we need to think about how we can spend existing budgets more effectively and look at developing new and innovative ways of providing care, treatment and support that will benefit an increasing number of people. In Wales there is a huge opportunity to do this. We have an incredibly skilled and dedicated work force with excellent third sector service providers and a strong track record in research. We feel that they Cancer Delivery Plan is helping cancer care and treatment move in the right direction, but a greater focus on organisational structure, processes and accountability will be needed if we are to reach the bold vision of a world class service by 2016.

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[1] Cancer Incidence, Mortality and Survival by Deprivation in Wales, Welsh Cancer Intelligence and Surveillance Unit report, July 2009

[2] De Angelis et al (2014) Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study The Lancet Oncology, Volume 15, Issue 1, Pages 23 - 34, January 2014

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[4] Breast Test Wales Uptake Mapping by Lower Super Output Area (LSOA): Screening Round 6 (for the approximate period Jun 2003 – Feb 2012), Produced by Screening Informatics, Screening Division, Public Health Wales

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[7] Wales Cancer Patient Experience Survey: National Report (2014) Produced by Macmillan Cancer Support, Quality Health and Welsh Government

National Assembly for Wales

Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Wales Cancer Alliance – CDP 18

Wales Cancer Alliance response to the National Assembly for Wales' Health and Social Care Committee inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.

1. Background

The Wales Cancer Alliance (WCA) consists of eleven voluntary organisations dedicated to promoting the best cancer prevention, treatment, research and care for people in Wales. Every year we invest more than £20m in Wales and contribute to the development of cancer policy.

Each member of the WCA will be submitting its own response to this Inquiry; therefore, this response by the WCA will focus on the overarching strategic issues that we believe are fundamental to the successful implementation of the plan. We will focus on the first question, ***"Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016."***

The Welsh Cancer Delivery Plan published in 2012 set out a vision to achieve a reduction in the impact of cancer on the lives of people and to improve outcomes by 2016 through:

- Preventing cancer
- Detecting cancer quickly
- Delivering fast, effective treatment and care
- Meeting people's needs
- Caring at the end of life
- Improving information
- Targeting research

The plan challenges each Local Health Board (LHBs) to plan and deliver high quality cancer care for their populations.

The Wales Cancer Alliance welcomed the introduction of the Cancer Delivery Plan and the creation of the Cancer Implementation Group (CIG) in June 2012. However, we believe that more work needs to be undertaken in particular in data collection and analysis of the information to inform action; more effective national planning; increased monitoring against performance measures and that more robust accountability structures need to be put in place.

2. Using data more effectively

Data to illustrate whether Wales is on course to achieve the outcomes and performance measures set out in the Cancer Delivery Plan by 2016, is available through the Wales Cancer Intelligence and Surveillance Unit (WCISU) and through other performance monitoring arrangements including the recent Wales Cancer Patient Experience Survey, cancer standards and peer review.

However, we remain concerned that there is not sufficient focus in place in Welsh Government or in the NHS to ensure that the data that is available is being used to drive the actions required to make improvements needed to cancer care consistently across Wales.

We believe it is unlikely that Wales will achieve the aspirations set out in the Cancer Delivery Plan without much greater and in depth analysis of the data and other information which is available, to identify where the gaps in services and performance are, and where improvements can and must be made.

3. More National Planning and Leadership

We welcomed the requirement set out in the Plan that LHBs have to produce their own annual cancer delivery plans which would help to tailor care to their local services and populations. However, there is significant variation in the content, depth and quality of different LHB plans, and this is likely to lead to greater variation in access to treatments and care from prevention and early diagnosis, through treatment and beyond.

Without national drive to achieve the goals in the plan, the current reliance and focus on planning and implementation at local health board level, will increase rather than reduce inconsistency in access to treatment and care across Wales.

We believe that some services need to be planned nationally on an all-Wales or on a network basis because of the complexity of cancer treatment and because often, patients will need to receive treatment with a number of multi disciplinary teams in a variety of hospitals which span a number of health board boundaries.

The lack of a national planning and support structure has meant that Wales does not have the capacity to manage initiatives on an all-Wales basis, including the project management of key elements of the plan such as taking forward work on early diagnosis which has been identified as a priority.

For example, the lack of a national approach has hindered the implementation of the key worker initiative. Roll out has been slow and the implementation of key worker role has been inconsistently interpreted and applied across health boards.

We recommend that a national planning structure and supporting processes are put in place which incorporate responsibility for better data collection and analysis of the information; for collating progress against the achievements of targets; for advising LHBs where the performance gaps in services are shown to exist; and for delivering the aspects of the plan which require a systematic national focus and commitment. This resource/team should also provide a forum for sharing and developing good and best practice.

Whilst we welcome the creation of the Cancer Implementation Group (CIG), in which the Wales Cancer Alliance has been recognised as a key member, we consider that the group does not have enough resources at present to support its work beyond the meetings particularly with regards to taking forward national initiatives.

A national planning structure and action team to support implementation of the Cancer Delivery Plan would help the CIG to work more effectively by bridging the existing gap between national policy and local implementation. We recommend that the Welsh Government considers the structures and processes that it would need to take forward and implement its ambitions.

We would like to see more evidence of national leadership, and priority setting which goes beyond a one year timeframe with more robust project planning underpinning each priority and with each clear objective having deadlines/ targets against which progress can be measured.

4. Clearer Accountability

Currently, it is unclear how the accountability structures and process for delivery against health board plans are working or how evidence is gathered which can be used as a tool upon which to benchmark performance.

We welcome the requirement for HBs to publish their individual cancer delivery plans and annual reports on their websites, and welcome the commitment to openness and transparency, which can be a one of the key drivers for change. However, in reality more formal accountability arrangements are also needed with clear expectations on delivery by health boards. Welsh Government must take responsibility for ensuring that where and when the need is identified that performance needs to be improved, that action is taken and additional support is provided.

The WCA believes that the ambitions as set out in the plan will not be achieved without more robust national planning, processes and structures to support implementation to gather informative data; carrying out proper in depth analysis to inform and identifying where action needs to be taken; overseeing national planning and all-Wales initiatives where needed; a more robust monitoring and accountability structure.

There needs to be acknowledgement that a more fundamental shift in thinking is needed about the scale and pace of implementation needed and the level of systems and cultural change required to achieve the ambitions set out in the plan by 2016.

5. Conclusion

In conclusion, the Wales Cancer Alliance welcomes the ambition and direction set out in Together against Cancer – Cancer Delivery Plan which was published in June 2012. We are now two years on from its publication and we are not yet assured that the aspirations set out in the Plan are being achieved at the pace and scale which we had hoped for. There remains significant work to do to ensure that the aims set out for 2016 are achieved across all cancer types and for every cancer patient in Wales. There remains too great a variation in outcomes and patient experience across hospitals and health boards which cannot be justified by local circumstances alone.

We call on Welsh Government to strengthen its approach to national planning and monitoring of progress in implementation. We need to look ahead more than one year with a focus on much greater collaboration across health boards and cancer teams where necessary to ensure patients receive timely and coordinated care.

A shift in thinking and approach is needed to ensure that the direction and ambitions as set out in the Cancer Delivery Plan, which we fully support, can be achieved for every cancer patient, no matter where they live in Wales.

Wales Cancer Alliance
4th April 2014

Membership organisations
Breast Cancer Care
Cancer Research UK
Cancer Research Wales
Clic Sargeant
Independent Hospices Cymru
Macmillan Cancer Support
Maggies
Marie Curie Cancer Care
Prostate Cancer UK
Teenage Cancer Trust
Tenovus

Appendix A

Wales Cancer Alliance
Priority Policy Calls

The Wales Cancer Alliance consists of ten voluntary organisations dedicated to promoting the best cancer prevention, treatment, research and care for people in Wales. Every year we invest more than £20m in Wales and contribute to the development of cancer policy.

The Wales Cancer Alliance welcomes the Welsh Government's Cancer Delivery Plan published in June 2012. We recognise the importance of the Delivery Plan in driving improvements in cancer services and call on the government to ensure continued momentum in the implementation of key commitments within the plan.

We believe that the voluntary sector has an important role to play in delivering improvements for people affected by cancer, and we look forward to working in partnership with the Welsh Government, the NHS and others to achieve this.

This document sets out the key areas where we believe further commitment is required and makes suggestions for action.

Preventing Cancer

It is estimated that up to half of all cancers could be prevented by healthy lifestyles. Not smoking, body weight management, active living, healthy food choices, low alcohol intake and staying safe in the sun can all help to reduce cancer risks.

We want to see;

- Improved public awareness of ways to reduce cancer risks and greater partnership working across sectors
- Opportunities for 'teachable moments' for prevention messages to be identified and supported.

A focus on early detection

We warmly welcome the areas that focus on early detection within the Cancer Delivery Plan and look forward to working with the government on their delivery.

We want to see:

- A centrally co-ordinated initiative to improve the early diagnosis of cancers in Wales
- An all-Wales public awareness campaign that highlights the common signs and symptoms of cancers and the importance of presenting promptly to a GP
- Robust evidence provided to Health Boards to guide local action.
- A national information campaign on the benefits of cancer screening that includes the voluntary sector
- Improved support for GPs in order to help them make timely referrals for cancer diagnoses and improved referral routes between primary and secondary care to encourage prompt onward referral.

Delivering fast effective treatment and care

We know that there are still inequalities in terms of access to services and treatments and that these can lead to inequalities of outcomes.

New processes should improve equity of access to cancer drugs but very little information is available to the public to determine the extent of progress made on this issue. There remains unequal access to treatment more generally; for example, new radiotherapy technologies or surgical techniques; and in both cancer and supportive services.

We want to see:

- Up to date data and more transparency in relation to access to cancer treatment
- Fair, clear and consistent processes across Wales to ensure patients are able to access clinically effective drugs
- People knowing what services are available to them; and
- Have equal access, irrespective of cancer type, geography, age, gender, socio-economic status, ethnicity, faith or disability to cancer specialist multi disciplinary teams
- Compliance with waiting time targets for urgent and non urgent cases
- Specific coordinated services for metastatic cancer patients and measured outcomes.

Meeting people’s needs

Cancer services should be focused on the individual needs of people and their families. People’s holistic needs – physical, emotional, spiritual, financial and practical are not always identified or addressed.

Each person should receive a personal care plan based on a holistic assessment of their needs and this should extend into the post-treatment phase.

People also tell us that they value having a named key worker to act as a coordinator, a touch point for questions and to signpost to services available to support people’s individual needs.

These changes would help to support many people to self-manage their condition after treatment and could therefore potentially free up resources and capacity for more complex cases.

We want to see:

- Assessment and care planning implemented for all people living with cancer
- Improved information and support to encourage self-management.
- Consistent interpretation and implementation of the key worker role across Wales
- An increased understanding by patients of the key worker role
- An end of treatment summary sent to patients’ GPs
- A more person-centred follow-up system to support cancer survivors.

Coordinating care

People tell us they want their care to be effectively coordinated, across the different parts of the statutory sector and the voluntary sector both during and after treatment. To achieve this, we need better coordination of health and social care services and between acute and primary care. Particular attention should be given to transition points such as at diagnosis, at the end of treatment and when patients are nearing end of life.

Clinical Nurse Specialists (CNS) and key workers play an important role in coordinating care. However we know that there is unequal access to CNSs and there is evidence of specialist nurse time being lost. We also know that implementation of the key worker role is patchy and inconsistent and that many patients are unaware of the support they can expect to receive from their key worker.

We want to see:

- A commitment to improved planning of health and social care services.
- Improved joint planning of individual patient care across acute and primary care services including the voluntary sector
- Extra support for people at key transition points.
- Data on specialist nurse provision across Wales.
- Research into the role of CNSs and the extent to which coordination of care needs are being met.
- Monitoring outcome measures on the implementation of the key worker role
- The findings used to inform practice to help assess the best utilisation of resources.

Caring at the End of Life

We know that more than 60% of people express the wish to die at home whilst the reality is that more than 60% of people in Wales die in hospital. We also know that people are concerned that they will experience pain at the end of their lives. Specialist clinical support is critical in ensuring that people’s end of life is pain and symptom-free. Carers and families should also receive the support and care they need.

We want to see:

- Increased emphasis on providing services in a community setting with appropriate resources to achieve this
- Greater integration of support across all organisations within and outside the public sector
- People being supported to have conversations about their wishes at the end of their lives.
- A Wales-wide conversation should be initiated to encourage people to discuss their wishes and views for end of life care.

Improving Information

There is a plethora of audit data collected, however we want to ensure that patients have the information they need to make informed decisions about their cancer treatment and care, and that Health Boards are able to assess and improve their services to cancer patients. Welsh Government also needs data to enable it and the public to hold Local Health Boards to account.

We want to see meaningful data relevant to patient experience, service quality and health outcomes collected, collated and acted upon.

We want to see:

- Local Health Boards acting on the results of the Welsh Government's all-Wales Patient Experience Survey findings to improve care and support for people and their families.
- Identifying dedicated outcome measures for patient experience and incorporating these into the new quality framework.
- Data and information presented in a transparent and easy to understand format so that everyone, including people affected by cancer, can understand the information.
- The creation of a supportive culture within the NHS for learning from patient experience and assessing and improving the quality of services.
- Collection of data on metastatic and recurrent diagnosis to enable effective planning and delivery of treatment and support to this group
- Supporting initiatives to make accessible information available for patients regarding treatment and care options and their availability

Targeting Research

Wales has been at the forefront of cancer research over the years with several members of the Alliance contributing to key advancements in detection and treatment for the disease. The development of the Wales Cancer Bank and the Wales Gene Park are key achievements that Wales should be proud of.

The Alliance would now like to see a greater focus on developing a cancer research strategy for Wales which gives a clear direction to those in the field of cancer research how they can contribute to the successful implementation of the Cancer Delivery Plan.

We want to see:

- People to be adequately informed and given access to the appropriate clinical trials as this is key for clinical research and improving outcomes.
- Clarity and focus in relation to the infrastructure, networks and funding streams that support cancer research in Wales
- More support for research into palliative and end of life care as well as survivorship and issues relating to living with cancer.

For further information please contact:-
Susan Morris, Chair, Wales Cancer Alliance SMorris@macmillan.org.uk Tel: 01656 867974

Wales Cancer Alliance
Breast Cancer Care, Cancer Research Wales, Cancer Research UK, Clic Sergeant, Hospices Cymru, Macmillan Cancer Support, Maggie's, Marie Curie, Myeloma UK and Tenovus. http://www.walescanceralliance.org.uk/

Agenda Item 6

National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Betsi Cadwaladr UHB – CDP 17

Ein cyf / Our ref: GL/DH/1311/915
Dyddiad / Date: 4 April 2014

Committee Clerk
Health and Social Care Committee
National Assembly for Wales

HSCComittee@wales.gov.uk

Dear Sir/Madam

Inquiry into the Implementation of the Welsh Government's Cancer Delivery Plan

Thank you for the invitation to provide feedback on the Welsh Government's Cancer Delivery Plan I hope the following information will be of use to the Health and Social Care Committee.

This response reflects the views of the Health Board and the North Wales Cancer Network. In doing so it reflects comments that are drawn from the perspectives of an NHS provider, commissioner and patients advocate.

Overview

Whilst it is the case that much of the Cancer Delivery Plan will be delivered by 2016 it is also likely that aspects of the plan will remain challenging and might not be delivered. Not only does the plan state that the incidence rate of cancer is increasing, it also makes reference to the challenging economic climate that not only existed at the time of publication but continues to exist at the time of this response. There must therefore be a concern that certain aspects of the plan cannot be delivered when set against a context of multiple priorities and diminished funding.

It is our view that access to evidenced based cancer treatment is consistently available to the people of Wales and as the evidence accumulates to support new therapies, these are adopted as soon as practicable in Wales. The key challenges for Wales and the Delivery Plan are early referral/diagnosis, end of life care and equity. Early diagnosis is the key to good outcomes in cancer and at this time rapid access to diagnostics provides perhaps the greatest challenge.

The plan has delivered much around end of life care, however it should be noted that 'end of life' features within a cancer plan, whilst our concern remains that end of life needs to feature in all plans related to chronic disease.

Cyfeiriad Gohebiaeth ar gyfer y Cadeirydd a'r Prif Weithredwr / Correspondence address for Chairman and Chief Executive:
Swyddfa'r Gweithredwyr / Executives' Office
Ysbyty Gwynedd, Penrhosgarnedd
Bangor, Gwynedd LL57 2PW
Gwefan: www.pbc.cymru.nhs.uk **/ Web:** www.bcu.wales.nhs.uk

Equity across Wales continues to be a challenge, and whilst the plan makes attempts to address this, it remains an area which could be difficult to deliver by 2016. An example here would be the number of approved Individual Patient Funding Requests (IPFR) for cancer drugs where there exists variation between different areas of Wales.

Specific Outcome Indicators and Performance Measures – Annex 3- Cancer Delivery Plan

It is unclear as to whether the plan can within the stated timeframe influence a reduction in the rate of increase in cancer incidence. A reduction in incidence will in the main depend on lifestyle changes eg smoking ban and it is unlikely that the benefits from such developments will be seen immediately. This said it is noted that more emphasis has been placed on the prevention agenda following publication of the plan and this is to be welcomed.

It is pleasing to see that a significant reduction in mortality accompanied by an increase in 1 and 5 year survival has been evidenced in the time of the plan and it is believed that this improvement can continue. This is particularly felt in North Wales where the cancer burden is the greatest in Wales but is matched by 1 and 5 year survival that is the best in Wales. This improvement in survival is however not matched by compliance with the cancer treatment waiting times which have proved difficult to attain in a sustained manner since the publication of the Delivery Plan – this said in most cases 9 patients in 10 are still treated within the target parameters. Failure to attain these targets consistently across Wales is, in our view, related in significant part to achieving an early diagnosis and the inequity mentioned earlier.

The last points above also reflect the stage of cancer when diagnosed and of course this influences the performance measure that, increasingly, patients are diagnosed with lower stage disease. This may be an issue that is difficult to improve significantly within the timescale of the plan as it will depend on early presentation to primary care from the public and prompt referral to cancer services as well as improved access to diagnostics.

Finally the plan has succeeded in ensuring that clinical trial activity is maintained, 30 day post treatment mortality data is collected and that all patients will have a key worker. Regarding the last two items we believe it reasonable to expect that by 2016 all 30 day post treatment mortality will not only be collated but interrogated. In terms of a Key Worker, all patients will not only have a key worker but one that provides greater impact on their care.

Summary of Outcomes- Annex1- Cancer Delivery Plan

Outcome 1- People are aware of and are supported in minimizing their risk of cancer through healthy lifestyle choices

The data suggests that since publication of the Delivery Plan there has been limited impact on the behaviour of the public in terms of lifestyle adjustment. This said it is also the case that at a local level there has been a significant increase in efforts within the NHS to address these issues. It is therefore possible that a more significant change may be apparent as the result of this plan. In North Wales this is reflected by new public awareness campaigns using public transport and cancer prevention talks in state schools.

Outcome 2- Cancer is detected quickly where it does occur or recur.

As previously mentioned it is this aspect where the plan at this time has its greatest challenge. Access to primary care is becoming more challenging as is direct access to diagnostics from primary care. In addition availability of more services 24 hours a day all year round is challenging and again availability of services more locally is difficult to achieve.

It is felt that this vital aspect of the plan has perhaps not been given the emphasis it should have been and the impact has been underestimated. It is these aspects of the cancer pathway that are subject more than any other to competing priorities and funding pressures and this needs to be addressed in the second half of the intended duration of the plan.

Outcome 3- People receive fast, effective treatment and care so they have the best possible chance of cure

In 2014 the Cancer Delivery plan has maintained momentum of speed of treatment and access to evidence based effective treatment. Whilst the issue of cancer waiting times has already been addressed it is worth noting that new emphasis is being placed on Peer Review – a process that features directly within the plan. This process is now addressing its fourth major cancer type and by 2016 all main cancer types will have been subject to the process with the first cohort of cancer types getting their first re-assessment.

Peer review alongside further developments within the cancer performance framework should ensure that the Delivery Plan ensures ongoing and improved quality assessment of cancer services.

Outcome 4- People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer

The Cancer Delivery Plan has been successful in providing greater emphasis on the holistic nature of cancer care and certainly at a local level significant efforts are being made with the third sector to address this person-centred issues. Whilst the various pieces of work are not yet complete there is a focus and momentum to have established and sustainable models of care by 2016.

In North Wales this is evidenced by projects regarding delivery of Key Worker, holistic care planning and rehabilitation.

Outcome 5- People approaching the end of life feel well cared for and pain and symptom free

Considerable progress has been made to date regarding the provision of palliative care including aspects of care involving the third sector and 7 day week working. The emphasis on seamless working across all sectors of the NHS and the 3rd sector is welcome and certainly evidenced in the day to day practice in North Wales.

Conclusion

It is noted that this inquiry takes place half way through the lifecycle of the Welsh Government’s Cancer Delivery Plan and as such certain aspects of the plan remain work in progress.

The themes within the plan remain valid as do many of the outcomes identified in the various annexes and to this extent the plan provides an important contextual framework for improving the delivery of cancer care.

Progress against the plan is evident especially in terms of ensuring the safety and quality of cancer treatment and end of life care. Progress is also evident in terms of holistic person centred care and many developments will be implemented in full by 2016.

The principal challenges for delivery of the plan remain at the front end of the cancer pathway – prevention and early diagnosis. The objectives for prevention though laudable may be slower to deliver outcomes and real improvement in the burden of disease may not be seen for many years rather than by 2016. The immediate concern however is achieving a rapid cancer diagnosis – this is the limiting factor that needs to considered further if the plan is going to achieve its wider objectives. In North Wales this is reflected by new public awareness campaigns using public transport and cancer prevention talks in state schools.

Yours sincerely

GEOFF LANG
ACTING CHIEF EXECUTIVE

National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from Velindre NHS Trust – CDP 31

Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan and whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016

Response from Velindre NHS Trust

Velindre NHS Trust comprises of 2 main operating Divisions namely:

- Velindre Cancer Centre, a specialist provider of non surgical cancer treatments
- Welsh Blood Services

In addition Velindre NHS Trust is 'Host' to a number of external organisations:

- National Specialist Advisory Group for Cancer (NSAGC)
- Cardiac Networks Co-ordinating Group of Wales
- National Collaborating Centre for Cancer
- NISCHR Clinical Research Centre
- NHS Wales Informatics Services (NWIS)
- Wales Shared Services Partnership (NWSSP)

Velindre NHS Trust's response to the 'Inquiry into progress made to date on implementing WG's Cancer Delivery plan' will seek to provide comments under each of the headings as per the terms of reference of the Inquiry.

1. **Is Wales on course to achieve the outcomes/performance measures as set out in the Cancer Delivery plan 2016**

   There has been good progress in some of the key areas within the Cancer Delivery plan. For example the Wales results from the recent Patient Experience Survey, run with the help of Macmillan, showed 89% patients rated their care as excellent or very good. In addition 88% of patients have been allocated a Clinical Nurse Specialist (CNS) and 86% patients said they had received the right amount of information. The Velindre results have been further analysed and show that they are very favourable in comparison to some of the best cancer centres in England and in fact in some domains Velindre's scores exceeded those of English cancer centres. However it is recognised the results were variable by organisation and cancer site, thus the focus between now and 2016 is to address the variability and ensure consistency for patients irrespective of where they receive their care or which cancer they have.

Other examples of positive progress include:

- The introduction of peer review which is driving up standards,
- Good recruitment rates into clinical trials
- Clinical engagement, especially with work to review the patient pathways, with some very good examples at both the South Wales Cancer Network level but also within Velindre Cancer Centre e.g. work to reduce the pathway for head and neck patients receiving Radiotherapy with a reduction in waiting times from 28 to 14 days without any additional resources
- Increasing numbers of patients consenting to their tissue being collected for the Wales Cancer Bank
- Creation of specialised Multi Disciplinary Team meetings (MDT) for metastatic cancers for some cancer sites, thereby ensuring patients with metastatic disease or diagnosis of secondary cancers are given the same care as those with first diagnosis.
- An increasing focus across Wales on the “survivorship” agenda and ensuring patients are living well with their cancer

Some of the key remaining challenges are:

- Continue to manage demand with the increasing incidence and patients surviving longer with cancer
- Diagnosing patients earlier – as this takes time before long term benefits are seen
- Improving Cancer information systems to improve communications between providers of care, including primary care, and to ensure good quality data to measure the outcomes

2. Progress made in reducing the inequalities gap in cancer incidence and mortality rates

Reducing the inequalities will have a long term effect on survival and mortality. It is important that NHS works with the public to seek to change behaviours and reduce risk of incidence of cancer. There are clear roles for Public Health Wales and Primary care in leading work in this area. It may be worthwhile considering whether targets/outcome measures for these organisations would be helpful in the achievement of this by 2016.

It is essential that Wales keeps up with new treatment developments in order to ensure an equitable access to clinical trials for patients and to continue to ensure that Wales recruits and retains high calibre clinical staff. We welcome the WG review into Access of new Technologies.

We are aware that the IPFR process is currently under review and we welcome this, as the current process can cause stress for patients, their families and the clinical staff caring for the patients and to avoid any perceived inequity.

The results of the Patient Experience Survey showed some variations in access to Key workers and the provision of care plans and we believe it'd be helpful if Wales is to achieve progress in this area by 2016, if there was some policies/agreement around these topics.

3. The effectiveness of cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups

In order to achieve the targets by 2016 there is need to continue to improve the national focus on prevention and we recognise the important role screening services play in prevention and early diagnosis.

Given the nature of the Trust screening service does not have a direct impact for the organisation. However VCC does recognise that it can, like all organisations, play a part in encouraging patients and their relatives to take up screening opportunities. The challenge is to reach the "harder to reach" communities.

VCC supports the "making every contact count" type initiative and would also welcome and support the development of some simple consistent messages for all to use.

4. Whether patients across Wales can access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner;

We recognise that reduced waiting times have a direct impact on outcomes and survival.
VCC has made significant progress over last few years in the reduction of waiting times for radiotherapy and chemotherapy treatments. For example in 2009 approximately 35% patients received radiotherapy within 28 days (with some patients waiting up to 11 weeks) and this is now 99%.

It is important that there is sufficient capacity in the future to maintain these waiting times – see later section re planning and funding.

The NHS is experiencing high demand for unscheduled care but the Acute Oncology Service (AOS) pilot between ABHB and Velindre Cancer Centre has proven a huge success and had an impact on patient's ability to access the correct type of care in a timely manner.
For example prior to AOS only 16% of the patients received correct investigation for neutropenic Sepsis, but now with AOS in place this has risen to 86%. Similarly following introduction of AOS 85% of patients suspected metastatic spinal cord compression had an MRI within 24 hours, compared to previously only 61%, and the mean time to definitive therapy from MRI has reduced from 50 hours to 24 hours.

Similarly there has been some progress towards 7/7 working so patients have same level of service irrespective of the day but, as across many specialties in the NHS, further work is required in this area between now and 2016. Good examples of the shift towards 7/7 are demonstrated by the all Wales palliative care work which has resulted in 7/7 working in all organisations.

As outlined earlier in this response Wales is reviewing the system of access of new technologies with the aim of ensuring that appropriate, clinically proven treatments/technologies are available to patients in Wales in a timely manner for the population .We welcome this review as we believe it is important for patients to have access to the most appropriate, clinically effective treatments.

With regard to the introduction of new drugs AWMSG have made improvements in their systems which have resulted in a reduction in the average time for an assessment to announcement. However further improvements to the system, including a system for orphan drugs, or drugs for rarer cancers is we believe essential to ensure equity for all patients.

Access to treatment i.e. waiting times are important and VCC welcomes the review of the 31/62 day targets, with the shift to more clinically determined targets. However it is important that the implications of the changes to the target are worked through prior to any formal changes.

Finally with regard to access to care in timely manner the IPFR process has some issues – but as outlined earlier it is under review with the aim of addressing and improving the process and we welcome this review.

5. The level of collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams.

There remains a very good level of collaboration across NHS organisations and with the Third Sector in the provision of cancer services. Examples include:

The Acute Oncology Service (AOS) pilot between VCC and ABHB has shown excellent results due to the high level of collaborative working. It has been shortlisted in NHS Wales Awards under the category of working across organisations.

There are projects funded by Macmillan which involve piloting electronic health needs assessments (e-hna) for patients and the development of care plans and key workers. These type of projects are great examples of work seeking to ensure ‘Person centred care’ is delivered by the MDT. Similarly Velindre Cancer Centre is working closely with Maggies in the development of a Maggies’ centre for patients in south east Wales – again an environment to deliver person centred care.

As outlined earlier in the response the All Wales Palliative care project provides another excellent example of collaborative working between the Third sector and NHS organisations for end of life care.

Recent events run by the South Wales Cancer Network to review lung cancer and colorectal pathways were only successful due to the close working of the organisations involved in delivering care. This type of work now needs to be rolled out across other cancer sites.

With regard to R&D the fact that in Wales research and treatment are delivered as part of a spectrum of care is a strength. Wales has improved access to trials as per the requirement of the cancer Delivery plan but if Wales is to maintain this level of access it requires organisations to continue to improve the way they work together in respect of the timeliness of start up, delivery and application of research. To support this increase in access it is important that there is a clear strategic drive and funding strategy to ensure that ALL patients have access to speedy delivery of research in line with the delivery plan.

6. Whether the current level of funding for cancer services is appropriate, used effectively and provides value for money

In the absence of comparative data it is challenging to comment on whether the current level of funding is appropriate, thus our response to this section will instead focus on the process for allocation of the funding, rather than the amount/level of funds.

In today’s financial climate the challenge for NHS Wales is to cope with the increasing demands for cancer services as more patients are diagnosed, more treatments are available and patients are surviving longer with their disease. Linking this to Prudent healthcare providers of cancer services need over coming years to consider potentially ineffective treatments/interventions and the impact on investment decisions. For example the provision of CNS and good palliative care has been demonstrated to improve the patient experience and in some studies to increase survival and quality of life compared to high cost drug treatments. VCC has a system in place to review deaths of patients within 30 days of SACT /chemotherapy treatments to ensure the clinical appropriateness of potentially high cost drugs, especially at end of life. All organisations should be encouraged to undertake similar reviews and VCC plans to roll it out to Radiotherapy between now and 2016.

Thus when considering investments Radiotherapy and Clinical Nurse Specialist (CNS) may prove more cost effective compared to some end of life medicines – but in Wales there isn't a process currently for the comparative assessments to be undertaken.

Similarly as patients live longer organisations need to develop new models of follow up so patients are less dependant .These models could include more focus on holistic needs through provision of support and rehabilitation.

The Acute Oncology Service (AOS) pilot has shown a reduction in length of stay and unnecessary investigations and hence a cost effective development.

Improved appraisal mechanisms for non drugs and technological interventions are vital to assist in decisions to invest in effective services that provide VFM. As outlined earlier there is currently a review in Wales into this area and we welcome that.

The Cancer Delivery Plan mentions the Health Boards should plan radiotherapy services through the Networks. There is we believe a need to strengthen the commissioning/planning arrangements between HBs and the Trust and that needs to be a focus for all organisations over coming years in order to prevent Wales falling behind other UK and European countries with regard to the development of radiotherapy techniques and capacity.

Developments in stratified medicine means there is a need, we believe, for a policy for the infrastructure of stratified medicine so patients can be selected for treatments on basis that they are more likely to benefit – thus for other patients this may avoid unnecessary treatment or fewer side effects.

With the Cancer Delivery Plan focus on R&D it is, we believe, vital all aspects of R&D funding are reviewed to ensure it is not having a detrimental affect on R&D in cancer services with a complex portfolio of funding streams which are a mixture of recurring and non-recurring.

Finally, it is our belief that the strategic planning of all cancer services could benefit from strengthening, through excellent clinical engagement and a cancer specific focus. As previously outlined there is a need for long term strategic capital planning, especially for radiotherapy equipment, so that Wales doesn't lag behind. Recent decisions e.g. to support development of SBRT/SRS services in Wales are a welcome step forward.

Agenda Item 7

Health and Social Care Committee

Meeting Venue:	**Committee Room 1 – Senedd**
Meeting date:	**Wednesday, 4 June 2014**
Meeting time:	**09.16 – 11.49**

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Wales

This meeting can be viewed on Senedd TV at:
http://www.senedd.tv/archiveplayer.jsf?v=en_200000_04_06_2014&t=0&l=en

Concise Minutes:

Assembly Members:	**David Rees AM (Chair) Leighton Andrews AM Rebecca Evans AM Janet Finch-Saunders AM Elin Jones AM Darren Millar AM Lynne Neagle AM William Powell AM Gwyn R Price AM Lindsay Whittle AM**
Witnesses:	**Mark Drakeford AM, Minister for Health and Social Services Dr Sandra Sandham, Welsh Government David Thomas, Welsh Government**
Committee Staff:	**Llinos Madeley (Clerk) Sarah Sargent (Deputy Clerk) Philippa Watkins (Researcher)**

TRANSCRIPT

View the meeting transcript.

1 Introductions, apologies and substitutions

1.1 The Chair welcomed members of the Committee, the Minister and his officials, and members of the public to the meeting.
1.2 Apologies were received from Kirsty Williams.

2 Inquiry into orthodontic services in Wales: Evidence session 3

2.1 The Minister responded to questions from the Committee.
2.2 The Minister agreed to ask Professor Stephen Richmond to consider the need for a minimum age for referral to orthodontic services, aside from the 2% of children quoted by the Chief Dental Officer as having an identified need for early referral.

3 Papers to note

3.1 The Committee noted the minutes of the previous meetings.

4 Motion under Standing Order 17.42(vi) to resolve to exclude the public for item 5 and under Standing Order 17.42(ix) for item 6

4.1 The motion was agreed.

5 Inquiry into access to medical technologies - consideration of the key issues

5.1 The Committee considered the key issues that have arisen from the inquiry.
5.2 The Committee noted its view that further exploration of access to medical technologies within primary care and social care is required before completing this inquiry. The Committee agreed to invite representatives from the British Medical Association, the Association of Directors of Social Services, Local Health Boards and Local Authorities, and any other relevant organisations, to explore these matters further.

6 Consideration of the Committee's forward work programme for the autumn term 2014

6.1 The Committee agreed to:

- undertake an inquiry into legal highs in the autumn term. The Committee will consider its approach to the inquiry in due course;
- invite the Older People's Commissioner to give evidence in the autumn term, particularly to discuss her review of residential care and her annual report;
- invite the Chief Medical Officer to attend a general scrutiny session in the autumn term as part of the Committee's programme of scrutiny of Wales's Chief Health Professionals;
- invite Government officials to provide a factual briefing on the regulations emanating from the Social Services and Well-being (Wales) Act 2014 in the autumn term, once draft regulations are published;
- raise, amongst other things, the following issues with the Minister for Health and Social Services and the Deputy Minister for Social Services during the scheduled general scrutiny session on 16 July:
  - the Auditor General for Wales' report on the management of chronic conditions;
  - GP recruitment, retention and training;
  - recent reports on cardiac surgery waiting times;
- consider matters relating to NHS Wales's complaints process, to be specifically informed by the Report on the Review of Concerns (Complaints) Handling within NHS Wales, led by Keith Evans, once the report is available.

Health and Social Care Committee

Inquiry into Progress made to date on implementing the Welsh Government's Cancer Delivery Plan

As part of the Health Committee's inquiry into the Welsh Government's Cancer Delivery Plan, the Assembly's Outreach team conducted five regional workshops with cancer patients across Wales. The workshops were conducted for a number of reasons including:

- To provide cancer patients, with first-hand experience of the Cancer Delivery Plan, an opportunity to share their experiences;
- To prepare participants for a focus group with Members of the Health and Social Care Committee;
- To inform the formal evidence sessions with witnesses including the Minister for Health and Social Care.

This document outlines the evidence gathered including the specific contributions of focus group participants.

Participants:

North Wales Cancer Patients Forum

(1 May 2014, Coleg Llandrillo College, Rhos on Sea)

There were 13 participants including patients, former patients, carers, volunteers and the Macmillan User Involvement Facilitator. A mixture of male and female participants from across North Wales were present.

The North Wales Cancer Patient Forum includes three 'locality groups' which are based around the three District General Hospitals in North Wales – Gwynedd, Glan Clwyd and Wrexham Maelor. An over-arching 'Strategic Group' meets in Rhos on Sea. Each group meets to discuss current topics affecting cancer patients in North Wales and ensure that the views of patients, friends and families are being heard.

NETs Natter Group

Assembly Communications: Outreach

(7 May 2014, conference venue, Manor Way, Cardiff)

There were a total of 25 participants including 18 patients, five carers and three members of staff.

Singleton Hospital Craft Group

(8 May 2014, Singleton Hospital, Swansea)

The group consisted of four female participants, two of whom have breast cancer, one of whom has lung cancer and secondary breast cancer, and one of whom has HPV cervical cancer.

North Caerphilly Breast Cancer Support Group

(12 May 2014, White Rose Information and Resource Centre, New Tredegar)

The group consisted of seven participants, all of whom were breast cancer patients. Three nurses/support staff were also present.

The Bracken Trust Cancer Group

(12 May 2014, Bracken Trust's offices in Llandrindod Wells)

A total of 10 participants took part – one participant spoke on behalf of his partner who has ovarian cancer, one patient had previously had breast cancer, three participants have prostate cancer, and two participants attended with their respective partners. The remaining participants worked for the Bracken Trust.

Notes from the Focus Groups

01. Are patients being adequately supported and receiving person-centred care (i.e. access to a Key Worker and a written care plan, access to sufficient information, receiving care in the most appropriate place for the patient)?
Were you supplied with a named Key Worker or Clinical Nurse Specialist?

North Wales Cancer Patients Forum

Some participants were unfamiliar with the term ‘Key Worker’, and did not know what it meant. Participants did not understand whether their clinical worker was their Key Worker, and felt that different terminology was being used by different hospitals, organisations and patients.

One participant, diagnosed with prostate cancer in 2006-07, said that he had been assigned a Key Worker who was very supportive initially during the first couple of months following diagnosis but, as time went on, the Key Worker gradually became more and more difficult to get hold of. He had been diagnosed with cancer again in 2010 and had not been allocated an initial key/clinical worker.

A carer whose husband was a cancer patient in receipt of cross-border treatment at two hospitals, said that the patient did have a Key Worker, but that things did fall through the net between hospitals on occasion, and the Key Worker was not always aware of the patient’s treatment and needs. However, the carer emphasised that there was always someone they could talk to, and that the oncologist had given them his personal contact details.

All participants agreed that having a point of contact, whether identified as a Key Worker or not, was very important.

‘NETs Natter’

Availability of Key Workers

Of the eighteen patients, nine had been diagnosed with neuroendocrine cancer post-2012. None of the patients had been assigned a Key Worker at any point during their care, although one patient had been assigned a neuroendocrine Clinical Nurse Specialist during their treatment in Liverpool.

Availability of Clinical Nurse Specialists and difficulty in diagnosing neuroendocrine cancer

The group highlighted that, at present, there are no neuroendocrine Clinical Nurse Specialists in Wales. A significant proportion of the group felt that while the symptoms of neuroendocrine cancer are similar to other cancers that attack the liver and bowel, many nurses and clinicians (especially General Practitioners) have difficulty diagnosing it.

Singleton Hospital Craft Group

Availability of Key Workers

Three of the four patients had been allocated a ‘Key Worker’ or designated Clinical Nurse Specialist. There was some confusion about the role of ‘Key Worker’ and the meaning of the term. The patients felt that many people contributed to their ‘care’ experience and noted that the level of care they had experienced in Singleton Hospital was excellent. One patient described personal experience of care delivered elsewhere where she had felt “*cattle-herded*” during her chemotherapy treatment. She said that once at Singleton, she was made to feel important “*and a person again*”.

North Caerphilly Breast Cancer Support Group

Lack of person-centred care

Some patients felt that they had not received person-centred care until they joined the Macmillan North Caerphilly Cancer Support group. Other patients noted that they had received excellent person-centred care and had had a direct link with a Macmillan cancer nurse as soon as they were diagnosed at hospital.

Availability of Key Workers

Two of the patients had been diagnosed with cancer before the Cancer Delivery Plan’s implementation in 2012. The remaining five had been diagnosed post-2012. Two patients confirmed that they had been allocated a named Key Worker; the remainder of the group had been allocated a Clinical Nurse Specialist. One patient had successfully requested a change of Key Worker as she had felt that her initial Key Worker was poor at providing her with support and “feedback” in terms of her treatment and “*lacked any interest [in me]”.* The change had been “*simple*” and she was very happy with her new Key Worker. A second participant described the lack of care she had received when allocated a new member of staff when her Clinical Nurse Specialist had gone on maternity leave.

Standards of care

The patients all agreed that there should not be discrepancies in the standard of care received by different people.

The Bracken Trust

Availability of Key Workers and Clinical Nurse Specialists

Two of the patients had been diagnosed with cancer pre-2012, and four

patients had been diagnosed during or post-2012. Three of the patients had been allocated a Key Worker, and one had been assigned a Clinical Nurse Specialist. The group noted that having a Key Worker or Clinical Nurse Specialist improved the patient's experience of treatment, and reassured them that they had a point of contact that they could utilise at any point during their treatment and aftercare. Some patients had had a poor experience of care and support from their District Nurse; while two others had received a high level of care and support.
Did you have an opportunity to discuss your care needs, and were you given a written care plan? If so, what was the benefit of this?

North Wales Cancer Patients Forum

Lack of awareness of written care plans

The majority of the group had received treatment either wholly or partially prior to the implementation of the Cancer Delivery Plan in 2012. One participant had received treatment since 2012 and had been given a written care plan.

The group agreed that there was a lot of jargon and unclear terminology. Participants had not been made aware of the purpose of a written care plan.

One participant referred to the Wales Cancer Patient Experience Survey and said that it reported that only 24% of patients of the Betsi Cadwaladr Health Board had a written care plan. The group thought that these figures suggested that awareness of written care plans is poor.

'NETs Natter'

Availability of written care plans

One patient who had been assigned a neuroendocrine Clinical Nurse Specialist had been given an opportunity to discuss her needs, in addition to receiving a written care plan.

Lack of opportunities to discuss clinical/care needs

The remainder of patients had received no appointments to discuss their clinical needs. They cited high rates of appointment cancellations, which resulted in further 4 – 6 month waits that delayed discussion of their future care needs. It was noted that, due to the nature of neuroendocrine cancer, it is difficult to foresee a patient's future care needs until he/she reaches a certain point in treatment.

Singleton Hospital Craft Group

Lack of written care plans

One patient had requested a written care plan but was refused. The other patients had not received written care plans. The patients, however, all agreed that their care and clinical needs were discussed often in appointments. Appointments ranged from one a month to bi-monthly and the patients all agreed that they had open access to their designated nurses or clinicians to discuss any issues as and when they arise.

North Caerphilly Breast Cancer Support Group

Availability of written care plans

Three of the seven patients had received a written care plan and found that it was an excellent way of discussing their care needs, in addition to obtaining a wider understanding of their disease.

The Bracken Trust

Availability of written care plans

Only one patient had been provided with a written care plan.

Differences in information between Wales and England

One terminally-ill patient said that they had difficulty understanding the discrepancy between services provided through the NHS in England and Wales. The group thought that more information about care needs should be provided, particularly where there are differences in the application of NICE guidance between the Welsh and English NHS, and that this could save patients a lot of disappointment in terms of understanding why they can/cannot receive certain cancer treatments.

Were you supplied with, or signposted to, sufficient information on your cancer and the effect it could have on your health, home life, work, finances etc.? Was that information accessible and easy to understand?

North Wales Cancer Patients Forum

Good access to information

In general the group felt that they had been provided with sufficient information about their cancer.

One participant who had been diagnosed with bowel cancer and prostate cancer said that there was sufficient information about bowel cancer but less information available about prostate cancer. One participant said that she had been provided with a lot of information about her husband's cancer and the treatment he would receive, but that they were not provided with information about finances.

Poor signposting

One participant involved in supporting people in the community stated that people are finding it difficult to get the information they need because signposting is poor. It was noted that, in the last year, the Macmillan Centre in Glan Clwyd Hospital has found that it has had a *huge number"* of people wanting information about different aspects of their treatment as they have not been signposted in the first place by the NHS.

The group felt that the majority of people received sufficient information about their cancer and treatment but not enough information about finances.

'NETs Natter'

Poor information and poor signposting

Without the opportunity to discuss their care needs and lack of written care plans, the patients had received little to no information to help them understand their condition. A number of participants described how they had tried to gain a better understanding of the cancer (both as patients and carers) which they found "scary". This self-exploration, and the information gathered from it, was often contradictory and difficult to understand. In terms of coming to terms with the effect of neuroendocrine cancer, patients, carers and nurses stated that they learn by experience "the hard way".

One of the nurses present at the discussion stated that there were not enough Key Workers/Clinical Nurse Specialists with the requisite knowledge and understanding of neuroendocrine cancer to be able to provide sufficient information and support to patients.

Singleton Hospital Craft Group

Good access to information

There was general consensus that patients were signposted to – or provided with – sufficient information about their cancer. One patient had been misdiagnosed for some time and found it difficult to access further information. Whilst it did not prove to be a significant problem for her, she felt that it could (due to the nature and rarity of her cancer) be a problem for other women. The patients also agreed that the majority of this information was provided through charities (like the Macmillan Cancer Support) rather than the NHS.

North Caerphilly Breast Cancer Support Group

Good signposting

The three patients who received a written care plan were also supplied with – and signposted to – sufficient information on their cancer.

Inconsistencies with regards to information and signposting

The remaining patients had had to find this information independently by picking up leaflets and booklets after their treatment. There was a particular lack of information provided about the effect of cancer on the future health, home life, work and finances of patients. The patients agreed that, upon diagnosis, the language used to explain their condition can be overly technical. Some had met with a Macmillan nurse immediately after their oncologist to talk the diagnosis through with them, and the patients agreed that this should be a mandatory part of everyone's care. They also argued that although some of the literature is easy to understand, it is something difficult for you to seek alone, saying that "*support and understanding is key*".

The Bracken Trust

Good signposting

The patients had all received booklets on their cancer, and some had been signposted to other information. Patients felt that the Bracken Trust was better at providing this signposting than the NHS. One patient explained that there is more information available now than there was in 2004 when he had been diagnosed. Another participant stated that more information should be given to patients about preventing cancer after recovery (for example, following the correct diet) although he appreciated that some cancers recur without cause. One breast cancer patient suggested that more information about diet and the

risk of weight loss should be given to those receiving chemotherapy.
Were your family given the information they needed to help care for you at home?

North Wales Cancer Patients Forum

Lack of information for families

The group generally felt that once treatment stops there is not much information about what the carer should do once a patient is at home. This includes information about all stages of cancer from treatment through to palliative care.

One participant said that psychological care for both patients and carers is lacking.

Lack of support for those without families

One participant noted that there is a need to avoid assuming that everyone has family around them to support them, and asked where people can access support if they do not have family.

'NETs Natter'

Lack of information for families

A number of patients stated that some of their family members attended appointments with them, but no specific information was given to help them understand on-going care needs. The participants agreed that more information should be provided to family members, particularly as patients aren't the only people who have to "live with the cancer".

Singleton Hospital Craft Group

Lack of information for families

Although the patients' families/next of kin all attended their appointments with them, none of them received one to one support or information about how to help care for patients at home. One of the patient's Clinical Nurse Specialists shared her contact details with her family and emphasised that they could contact her at any point should they need to.

North Caerphilly Breast Cancer Support Group

Lack of information for families

The patients stated that none of their families were given the information they needed to help care for them at home.

Bracken Trust

Lack of information for families The patients stated that carers should also have a care plan, in addition to the patient, and noted that there is a lack of support for families across the board (in terms of healthcare) to help them come to terms with a family member's illness. One participant had received advice on financial support during their partner's treatment, but said that they had not needed it.
If you have any long term side effects as a result of the cancer treatment, have you received the necessary information and support for these?

North Wales Cancer Patients Forum

Lack of information and support for long-term side effects

One participant felt quite strongly that people do not receive the information they need about the possible side effects of cancer and its treatment.

It was noted that many people have problems following treatment such as chemotherapy and there is very little information available in order to deal with these problems. The group felt that the follow up to radiotherapy was not very good; one participant still suffers from severe side effects following radiotherapy treatment and had not been given any information about this.

Knock-on effects of lack of information

The group expressed concerns that if people are not followed up after their treatment, health practitioners may not learn about potential side effects of cancer and its treatment. The group was also unclear about how, if at all, lessons learned from their experiences were captured and used to help with the treatment and care of others.

'NETs Natter'

Lack of information and support for long-term side effects

Living with neuroendocrine cancer was compared to suffering from diabetes – the importance of balancing the clinical aspect of the cancer (such as treatment) with the management aspect of the disease (living with the cancer, taking medication and the daily side effects) was noted. The patients stated that they were wholly unprepared for dealing with the psychological effect of the cancer, noting that many of the symptoms discouraged patients from leaving their homes or making travel arrangements.

Singleton Hospital Craft Group

Information on long-term side effects

Three of the four patients explained that they were provided with the necessary information and support on the long-term side effects of their cancer treatment.

The remaining patient stated that her district nurse did not have the requisite knowledge to know how to treat her in the community and to provide her with the same level of support provided at hospital. She said that her district nurse had been offered training in order to support her HPV treatment, but that she often felt that she was supporting and co-ordinating her own care.

One patient felt that she was wholly unprepared for the psychological and practical effects of her cancer treatment, and felt that she could have received some more support with regards to having to give up her career and the resulting financial implications.

North Caerphilly Breast Cancer Support Group

Good information on long-term side effects

The patients generally agreed that they have received the necessary information and support about the long term side-effects, and feel that this is provided more than adequately by the Macmillan Cancer Support Group.

Bracken Trust

Lack of information on long-term side effects

The patients all agreed that they had not received the necessary information about the long-term side effects of cancer and its treatment.

Information about the financial impact of cancer

Many thought that patients should be able to claim back the costs of travelling to and from hospitals outside of their local health board area. It was also noted that more support is needed for patients to improve their understanding of how they can find funding for prosthetic body wear and wigs.

02. What actions need to be taken to ensure cancer is detected quickly (for example, increasing the level of uptake of cancer screening services, more direct access to diagnostics for GPs, improved referrals by GPs regarding waiting times)?
What actions need to be taken to ensure cancer is detected quickly?

North Wales Cancer Patients Forum

Lack of specialists

One participant noted the paucity of specialists in certain types of cancer across North Wales, for example skin cancer, for which clinic appointments have been postponed more than once, sometimes at short notice The participant also felt that there is a discrepancy between services in north and south Wales, and that shortages in north Wales are not being addressed in a timely manner.

Delays and misdiagnosis

One participant noted that once someone has cancer symptoms they are put on some treatment or medicine and told by the GP to return in a month if the symptoms are not better. They thought that delays such as this could have knock-on effects for referrals further along the line, including waiting for CT scans or relevant screening. Some participants had waited as long as 3 months between presenting themselves with symptoms and getting access to cancer screening.

The access GPs have to screening was deemed insufficient.

Issues relating to gender-specific cancers

One participant who had been diagnosed with prostate cancer and then bowel cancer said that there is little being done to promote men's health and the screening available to men for things like prostate cancer.

'NETs Natter'

Delays and misdiagnosis

The participants felt strongly that GPs should have a greater awareness of the symptoms of neuroendocrine cancer and be more willing to refer patients for scans. One participant said that it took seven years from her initial visit to her local GP surgery to final diagnosis. Participants said that because neuroendocrine cancer does not sit within oncology, it is not within a clinician's radar for detection. It was argued that a more cost-effective method of detection would be the routine use of urine testing.

Singleton Hospital Craft Group

Quick diagnosis and detection

The patients all felt that quick detection was key for diagnosis.

Delays and misdiagnosis

Two of the patients had been misdiagnosed for a significant period of time (up to one year) which had resulted in their cancers being categorised T4[1]. One of the patients suggested that individuals should be given the opportunity to elect and pay for a scan to be carried out, and reimbursed if anything is detected.

Another patient said that dealing with referrals in a timely manner was very important. She noted that her GP had referred her for an urgent appointment at the breast clinic, but that for her own peace of mind she had elected to have a private scan. She received this within two days, but the letter for her urgent appointment did not arrive until 6 weeks later. She felt that more could be done to encourage timely referrals from the GP to diagnostic testing.

One patient felt that more family GPs should be allocated. She explained that most of her GPs were locums and she did not see the same one twice at any point prior to diagnosis. She felt that this may have contributed to the time taken to diagnose her.

Issues relating to gender-specific cancers

As individuals diagnosed with gender-specific cancer, the patients explained that male clinicians only make appointments with them when a female nurse is available to sit-in too. It was suggested that this could contribute to the time delay in diagnosis/treatment. The patients all stated that they would have been comfortable to meet with their clinicians without a female nurse being present.

North Caerphilly Breast Cancer Support Group

Delays and misdiagnosis

The patients all agreed that the age for mammogram screenings should be lowered. One patient had been diagnosed at the age of 40 and would have been a decade away from her first screening. She was diagnosed with a T3[2] aggressive form of breast cancer which, undetected, would have taken her life within 18 months.

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[1] Most types of cancer have a staging system numbered one to four. Category four is given where the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

[2] Category three staging is often given when the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in the area.

Awareness raising The patients agreed that more should be done to raise awareness of the fact that cancer is a life-threatening illness, rather than an illness that manifests from smoking or an unhealthy lifestyle for example. Some cancers develop without symptoms and often without reason. As such, they felt that young people should be taught how to check their bodies for lumps. **The Bracken Trust** *Awareness raising* The patients agreed that more should be done to raise awareness of cancers at an earlier age, and particular attention should be paid to GP referral times and detection.
Did you/do you attend regular cancer screening services?
Participants in all groups noted that they had participated in screening and continue to do so, but that screening services should be available at an earlier age. Furthermore, the North Caerphilly Breast Cancer group noted that more awareness should be raised to ensure that patients receiving treatment should continue their screenings in order to ensure that cancer is prevented from developing elsewhere in the body. The NETs Natter group reported that some patients had waited up to 8 months for lung and heart checks ups. Participants from the Bracken Trust noted the need to draw attention to the fact that male cancers can request a PSA from the GP at any age.
What could be done to encourage more people to take advantage of cancer screening services?

North Wales Cancer Patients Forum

Raising awareness

One participant said that people need to take more personal responsibility for their health.

The group felt that more is being done now to make people aware of cancer screening services but that this it is still not enough. They felt that we need to talk to children in schools about cancer and we need to speak to them in the way they want to be spoken to. They need to be educated on the information that is available and where they can find it. The group felt that children need to be shown something that will force them to take action.

'NETs Natter'

Raising awareness and understanding of neuroendocrine cancer across the board

There are no screening services for neuroendocrine cancer, and the participants stated that there needs to be a greater understanding and awareness of the condition and the symptoms at all levels of health care.

Singleton Hospital Craft Group

Raising awareness

Some of the patients stressed the importance of breaking the "embarrassment and comfort" barrier in order to take advantage of cancer screening services. One patient stated that anyone who is sexually active should be smear tested, as HPV cancer and viruses can be immunised against. It was noted that outside the UK young people are taught to check for breast and testicle lumps; the patients all argued that this should also be the case in our secondary schools. They said that this learning should be visual, and show the effects of cancer. They thought that personal health should be at the top of the agenda, along with nutrition.

Genetic testing

One patient raised the possibility of introducing more routes to "genetic testing", to add to the existing routes available to women who come from families with a long history of breast cancer.

North Caerphilly Breast Cancer Support Group

Raising awareness The patients agreed that in order to encourage more people to take advantage of cancer screening services, advertising should be shown during prime time television and targeted carefully to the relevant audiences. **The Bracken Trust** *Raising awareness* For more people to take up cancer screening services, encouragement should come in the form of public health campaigns, in addition to services being made available to individuals who come from families who suffer from a high incidence of cancer.
How proactive and informed was your GP in assessing and referring your symptoms?

North Wales Cancer Patients Forum

Delays and misdiagnosis

One participant noted that it took 10 months for him to be diagnosed with prostate cancer because his symptoms were initially treated as an infection.

Consistency of GP services

The group felt that GPs were sometimes proactive, however not everyone has a consistent family GP meaning that the GP is reliant on filed information rather than using first-hand knowledge about a particular patient. Members of the group were worried that seeing more than one GP could result in inaccurate information being recorded or transferred.

Patients' experiences varied significantly, but in general the group felt that a lot needs to be improved in general practice.

'NETs Natter'

Lack of awareness of neuroendocrine cancer/NETs at GP level

The patients all felt that GPs lacked the requisite knowledge and understanding of neuroendocrine cancer to be able to assess their symptoms as being synonymous with the disease. This, in turn, had a knock-on effect on referrals. The majority of patients were misdiagnosed when they had presented themselves, and had spent between six months to seven years being treated for conditions such as Irritable Bowel Syndrome.

Singleton Hospital Craft Group

Delays in being referred for scans

In general, the patients felt that their GPs were proactive and informed in assessing and referring their symptoms, but the lack of urgency to refer them for scan testing meant that two of the patients' cancers spread. One participant felt that her GP surgery was very poor identifying her symptoms, although the level of care she has received since then had been excellent.

North Caerphilly Breast Cancer Support Group

Proactive and informed GPs

The patients generally felt that their GPs were proactive and informed in assessing and referring their symptoms; for one patient the time from screening to diagnosis was three weeks. One patient said it happened "*a little too fast*" for her, and said that she had not had much time to come to terms with what was happening to her. On the other hand, she said that the support she had received from the nurses was outstanding and helped put her at ease.

The Bracken Trust

Proactive and informed GPs

The patients all agreed that their GPs were very proactive and informed in assessing and referring their symptoms.

03. What improvements can be made so patients receive fast, effective treatment and care (e.g. fast access to appropriate treatment, well-coordinated services, access to clinical trials and research)?

Do you have any experience of receiving cancer care across different hospitals or across primary, community, secondary or social care settings, and if so, what is your view on how your care was coordinated?

North Wales Cancer Patients Forum

Poor cross-border coordination

Some participants within the group had experience of cross-border treatment. They felt that there is a lack of co-ordination between different hospitals. They reported the need to tell the nurses or oncologists at one hospital what had happened in another hospital with paperwork not always passed between them. There was a strong feeling that communication between hospitals is lacking.

Good coordination across care settings

One participant felt that he had a good experience of communication between his GP and hospital consultant. His consultant sent a review of his condition and his treatment to his GP and he also received a personal copy of this information.

'NETs Natter'

Lack of coordination

The vast majority of participants stated that the care of neuroendocrine cancer should be better coordinated, as they felt that they were asking for treatment all the time rather than receiving it. They highlighted the need to build momentum in treatment from the first test onwards, saying that there were lapses in time between tests and a lack of a sense of urgency by clinicians.

Singleton Hospital Craft Group

Good coordination

The patients all agreed that their care was generally well-coordinated. However, they stressed the importance of information sharing and the need to make everything accessible electronically for all medical staff. They argued that clinicians from all departments and approved care settings should be able to access an individual's medical record.

Lack of coordination

One patient, having received care at two different hospitals, stated that her information wasn't shared adequately between them.

North Caerphilly Breast Cancer Support Group

Better communication across care settings needed

The patients all had experience of receiving cancer care across the south Wales region. They felt that communication needed to be prioritised in order for care to be better coordinated. They also noted that better communication between the hospital and the aftercare teams is required. Some spoke of experiences where District Nurses showed a "*lack of care and respect*" when visiting, failing to read notes and asking the patients "*what they were there to do*" on occasion.

The Bracken Trust

Better communication across care settings needed

The patients all had experience of receiving cancer care across different hospitals. The patients agreed strongly that better communication between departments and hospitals is required, and stressed the need to send copies of letters to patients so that they are "kept in the loop" about the discussion of their care.

Were you approached with regard to participating in a clinical trial, and if so, what was your experience of this?

North Wales Cancer Patients Forum

Many of the participants within the group had been approached about participating in a clinical trial.

One participant said that her experience with clinical trials had been very good and that she believed that they helped to save her life. Her sister was diagnosed subsequently with the same cancer and the drugs from the clinical trial that she had been involved in were then used as part of her sister's treatment.

'NETs Natter'

One participant has taken part in three clinical trials: two in the UK, and one pending in Germany. She had enjoyed taking part and welcomed the offer to participate.

Singleton Hospital Craft Group

None of the participants were approached with regards to participating in clinical trials.

North Caerphilly Breast Cancer Support Group

One of the patients took part in a five-year clinical trial that compared the effects of Anastrozole and Tamoxifen. The clinical trial came to a close last year. She had enjoyed the experience, and felt as though she had an excellent point of contact throughout her treatment.

The Bracken Trust

One of the patients was approached to take part in a clinical trial, but his clinician stressed her desire to manage his treatment personally. One participant outlined that clinical trials are only really offered to those where previous treatments had proved unsuccessful.

04. What improvements can be made to ensure people are aware of, and supported in, minimising their risk of cancer through healthy lifestyle choices?

Assembly Communications: Outreach

Do you believe the public awareness campaigns about cancer risk factors (for example smoking, alcohol and obesity etc.) are sufficient? If not, why not, and how could they be improved?

Did you access any of the public health services available to promote healthy lifestyles (such as obesity, alcohol or smoking cessation services) and if so, what was your experience of them?

North Wales Cancer Patients Forum

The group as a whole felt that the key word to consider when discussing public awareness of cancer risk factors is motivation. They felt that people refuse to take responsibility for their own lifestyle. They argued that making people more aware of the effects of their lifestyle decisions may motivate them to change their decisions. There was recognition, however, that finding ways to motivate people can be difficult.

The group felt that educating people about the risks of cancer from a young age is very important, but there was a feeling amongst the group that there are too many public awareness campaigns about cancer risk factors. The group queried whether people take any notice of them and wondered whether messages were being diluted as a result of the sheer number of campaigns.

One participant noted that changing legislation has an influence from time to time, for example the legislation to ban smoking in pubs. It was noted that being bombarded with campaigns everyday does not have the same effect. The group asked whether any research has been done to see whether these campaigns actually work.

Many of the participants felt that existing initiatives are not used to best advantage for example Flying Start sessions – the Welsh Government's targeted Early Years programme for families with children under 4 years of age in some of the most deprived areas of Wales – were cited as an opportunity to promote lifestyle decisions and to give people advice about cancer.

'NETs Natter'

The group argued for increased awareness amongst General Practitioners of neuroendocrine cancer symptoms. It was explained that neuroendocrine cancer does not necessarily manifest itself as a result of poor lifestyle choices, but may stem from genetics or hormonal imbalances. It was felt that having specialist neuroendocrine nurses would be the best option for patients and that teaching about this form of cancer should form part of the GP's Continuous Professional Development.

Singleton Hospital Craft Group

The patients agreed strongly that cancer campaigns were insufficient for young people and cancer screenings should start at a younger age.

One patient outlined the need to keep educating women about breast cancer: "*Breast cancer isn't just a lump…there are other ways of identifying it through* *tissue strands…you need to know your own body, and young women should be taught to explore in order to be able to understand when something's wrong".*

One patient accessed the exercise referral scheme, but it had not been developed fully enough in order for her to take advantage of it. She said that she had received this information at a Cancer Recovery Show and not through the NHS.

North Caerphilly Breast Cancer Support Group

The patients felt that more gender-targeted advertising should be shown on television. Some patients stated that there were too many health campaigns which cause confusion, particularly with regards to "what's healthy to eat". The group had a discussion about the lack of information available in the public sphere about the effect of food and drink additives. As mentioned previously, the group also stated that cancer campaigns should not merely focus on a healthy diet, as many cancers develop without cause or symptoms.

Two of the patients accessed public health services, but these were referred to them through Macmillan as opposed to the NHS. One attends a fitness class which is delivered jointly through Macmillan and the local Communities First scheme. The other utilised a reflexology treatment referral through Velindre which helped her regain focus on her general well-being.

The Bracken Trust

The patients all agreed that public awareness campaigns about cancer risk factors were insufficient. The group noted that there is a lot of competing information, particularly with regards to diet. One of the participants felt that public health messages often "*talk-down to the public which is patronising…people cannot be expected to live up to this high expectation of what constitutes a healthy lifestyle*".

Another participant and patient felt that information should be shared with children of all ages, rather than allowing them to be sheltered from the effects of cancer: "*there needs to be an open conversation about cancer which may in future…encourage them to take up screening*".

Health and Social Care Committee

Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Note of focus group discussion 14 May 2014

1. The Health and Social Care Committee invited people with experiences of cancer services in Wales to participate in focus groups, arranged in partnership with Macmillan Cancer Support and the Wales Cancer Alliance. Members facilitated individual focus groups, seeking participants' views on three main themes, as well as any other points that they wished to raise, and the outcomes of the discussions were captured during a plenary session. This note focuses mainly on the plenary discussions, but also includes some issues raised in individual groups.
2. There was variability in the experiences of patients from across Wales and with different types of cancer. Patients felt that the Cancer Delivery Plan itself sounded good, but that it was not reflected in their experiences as patients.
3. Patients thought that they should not have to fight for the treatments or drugs that they needed, but that instead there should be recognition that each patient is an individual, who needs to be treated in the best way for their particular cancer and circumstances.

Theme 1: what actions need to be taken to ensure that cancer is detected quickly?

Diagnostics

4. Patients had mixed experiences, and expressed concerns about the ability of GPs to identify specific cancers. They said that in many cases repeated visits to GPs were required before receiving an appropriate referral. Some patients expressed frustration and disappointment that

they had to fight for their symptoms to be taken seriously by their GP. To address this, they felt that GPs needed access to the right initial and ongoing training, both in terms of symptoms, and also appropriate ways to communicate with people without providing false reassurance.

5. Some patients mentioned the role of other primary care services in diagnosis, for example dentists and nurse practitioners.

6. Patients felt that waiting times to access diagnostic tests were too long, particularly in relation to specialised tests or less common cancers. There was frustration that long waiting times could contribute to the stress on an individual, but could also mean that the cancer could progress or metastasise, or impact on the period of sick pay available to the individual. It was also noted in some groups that later diagnosis could lead to higher costs for the NHS due to the increased complexities of treating more developed cancers.

7. Some patients, particularly those referred via the non-urgent route, had paid for private diagnostic tests to avoid lengthy waiting times, but expressed discomfort about having had to do so, and that not all individuals could afford this option. One patient said that had she known cancer was a possibility in her case, she would have paid for a private test. Others said that had they been more aware of the 10-day target to see a consultant they would have chased appointments earlier themselves. They also thought that GPs should have a role in chasing up referrals.

8. Concerns were raised about access to mammograms, particularly that women over 70 are not aware that they have the right to request mammograms, and there was a view that the age at which women are invited for mammograms should be lowered from 50 to 47, as is the case in England. Similar concerns were expressed in relation to prostate-specific antigen tests for men, as many men are unaware that

they have a right to request tests and awareness of the risks of prostate cancer is low.

9. Concerns were also heard that some patients were only diagnosed after attending A&E, which could cause additional stress for patients and additional pressures on services. According to Cancer Research UK approximately a quarter of cancer cases in the UK are diagnosed through emergency admission to hospital.

10. Patients were also unhappy about refusal of applications for genetic testing, which they felt overlooked the preventative role of genetic tests, and about refusals for applications for second opinions.

Theme 2: what improvements can be made to ensure that patients receive fast and effect treatment and care?

Access to treatments

11. The group raised concerns about the consistency of access to cancer medicines, therapies, surgical interventions and clinical trials, and thought that in many cases there was a 'postcode lottery'. There was no general consensus on whether a cancer drugs fund should be established for Wales, but there was a sense that the Individual Patient Funding Request (IPFR) system can be frustrating, and that there is inconsistency about the way that decisions are made by different oncologists and different Local Health Boards (LHBs). There was also a feeling that the clinical reasoning behind decisions to allow or deny treatment was not always communicated clearly to patients. There was a view that an appropriately funded all-Wales approach is required to ensure equity of access, but also that oncologists should have more of a role in the decision making process as they had the best knowledge and understanding of the individual patient.

12. Patients felt that generally, once you were within the system, there was good monitoring of individual cases, but that treatment could sometimes be disjointed and suffer from delays. Some participants

raised the breast cancer treatment pathways, and said that they were too drawn out and lengthy. One suggestion was that there should be a presumption that a patient will wish to proceed with treatment, allowing it to be scheduled at the earliest opportunity to avoid delays once a patient has met with their consultant for the first time.

Access to specialist services

13. Patients' experiences were mixed, particularly in relation to less common cancers. Services could be disparate, and gold standard care was not always available. There was recognition however that cancer specialist centres might be at some distance, or even in England, and patients were content to travel in order to receive the best care. Some patients present had moved from England to Wales, or vice versa, to receive the best care for their particular cancers.
14. There was concern about the availability of radiologists in Wales.

Delivery of treatment

15. There were mixed views on the environment in which services were delivered, with some having had positive experiences while others described negative experiences. One patient said they had had to wait in their car to avoid the stressful environment in which their treatment was being delivered, and other patients referred to a lack of privacy. There were also concerns about the availability and quality of out of hours services.

Access to aftercare

16. Patients felt that aftercare was extremely limited, and that there was not enough recognition of the effects the fear that the cancer would recur could have. They felt that there was a role for GPs and community nurses in providing aftercare in the community once a patient had been discharged from secondary or tertiary care, and said

that this should be built into GP contracts and performance actively monitored. One group felt that cancer should be included in the GP Quality and Outcome Framework.

17. A number of participants felt that there was insufficient information available about continuing screening following treatment, and that screening intervals throughout aftercare should be closer together.

18. Some patients raised the positive effects wellbeing type centres had on their lives during and after diagnosis and treatment. It was felt that the psychological issues of patients were not being adequately addressed and more support in this area was required.

19. Third sector cancer rehabilitation programmes were praised, particularly where interventions such as occupational and speech therapy are required. It was noted that such programmes are not available uniformly across Wales.

Theme 3: are patients being adequately supported and receiving person-centred care?

Patient empowerment

20. There was a feeling that patients needed to be more empowered, with a clearer idea of their patient rights.

21. Patients raised the issue of access to their patient notes, as patients in Wales were not always aware they could request to receive copies.

Care plans

22. Few of the patients present had written care plans. Some patients felt that there was a lack of engagement with social services departments with regard to their care.

23. Given that people are living with cancer longer, and in many cases may have multiple conditions which could impact on each other, the patients felt that their care plans should reflect this, and that medical

professionals should work collaboratively and ensure a joined up approach is taken.

Provision of information for patients

24. The groups were concerned that often a lot of information is provided to patients at the point of diagnosis, when they may not be well placed to take in details, and felt that time needed to be built in to reflect and digest the information. It was noted that individual preferences need to be taken into account when providing information about cancer diagnosis and treatment, and provision adapted accordingly.
25. There was thought to be a lack of financial information and advice in relation to benefits and the impact on cancer patients' earnings.
26. Patients were concerned that good practice on the provision of information is not consistently shared and implemented throughout Wales, for example, the blue book in north Wales is not available in south Wales.
27. Patients found NHS websites in Wales very difficult to navigate, and said that they contained less information than the equivalent sites in England. They said that it could be confusing as to who you would see next and what would happen, and felt that having access to treatment and diagnostic flowcharts could help them to understand their cases and ask questions.

Key workers

28. Patients agreed that it was important to have someone to go to with questions or concerns (whether this was one person throughout the treatment, or a specialist at each stage), but there was mixed understanding and awareness of the role of key workers, and some patients felt that charities were filling this gap. Some patients knew that they had a key worker, others did not know who their key worker was, or if they had one. It was suggested that the provision of a key

worker for each cancer patient was not uniform across Wales. One patient said that he had been given a generic key worker contact card, which had a switchboard number and no individual name. In some cases patients expressed concern about the workload that individual key workers were allocated.

Clinical nurse specialists (CNS)

29. Patients were very positive about the role of specialist nurses, but were concerned that if a nurse changed roles or was off sick then relationships were interrupted. Where individuals had poor experiences of clinical nurse specialists this was often linked to the high workload of the nurses impacting on their capacity and performance

Support groups

30. Access to support groups was felt to be very important, but patients felt that more should be done to signpost them to groups that could provide support, rather than leave patients to find them themselves.

Information and support for patients' families

31. There were mixed views on the role of the NHS in providing information and support to patients' families – some considered this to be very important to the provision of support for the patient, and others felt that services to cancer patients should be prioritised within limited resources. Some patients saw looking after families as the role of the third sector.

Other issues that were raised

Awareness and public education

32. Patients were in agreement about the importance of an early diagnosis, and the need to further raise awareness of symptoms and risks, particularly among young people. Suggestions were made that, given cancer awareness messages are consistent, the UK nations should work more closely together to produce public awareness campaigns, and that more use should be made of social media to target young people in addition to TV campaigns and work in schools.
33. There was concern about the low take-up of screening programmes such as the bowel cancer screening programme, and a feeling that more needed to be done to inform people about the benefits of screening.
34. Patients were interested in the Welsh Government's over-50s health check, but felt that it should include face to face contact with a GP.
35. Some patients felt that conversations about cancer can sometimes be dominated by discussions of female cancers, and that to address the imbalance in cancer gender statistics there was a need to target men to encourage them to be more proactive about their health.
36. Patients were concerned that the system is already at its capacity, and may not be able to respond to an increase in demand as an outcome from public awareness campaigns.

Statistical information

37. Patients were dissatisfied with the availability and transparency of statistical information in relation to cancer, and felt that more transparency would allow patients and politicians to hold the Welsh Government to account. Specific concerns included:
    a. the way that individuals referred for treatment over the border is recorded in waiting time statistics;

b. a lack of statistical information in relation to secondary tumours.