

## Health and Social Care Committee inquiry into gynaecological cancers Cancer Research UK Response – January 2023

### Introduction and recommendations

Cancer Research UK welcomes the opportunity to respond to the Health and Social Care Committee's consultation on gynaecological cancers, and the spotlight this inquiry will give to gynaecological cancers in Wales.

Each year, around 1,200 people are diagnosed with gynaecological cancer in Wales.<sup>1</sup> The incidence rate for gynaecological cancer is significantly higher in Wales (72 cases per 100,000 female population) compared to the UK average (68 cases per 100,000 female population).<sup>2</sup>

Each year, around 470 people die from gynaecological cancer in Wales.<sup>3</sup> The mortality rate for gynaecological cancer is significantly higher in Wales (26 deaths per 100,000 female population) compared to the UK average (24 deaths per 100,000 female population).<sup>4</sup>

In addition, there is some evidence from the International Cancer Benchmarking Partnership (ICBP) to suggest that ovarian cancer patients in Wales do have longer patient intervals and primary care intervals compared to countries with higher survival such as Denmark<sup>5</sup>.

Our submission highlights important issues regarding awareness and symptom knowledge of gynaecological cancers, access to primary care and long waits for diagnostic tests and treatment for some cancers. We also look at the HPV vaccination programme, where improvements can be made, and where there is opportunity for innovations in the gynaecological cancer space.

### Recommendations for Welsh Government, the Wales Cancer Network and Public Health Wales to consider:

- Explore innovative approaches to communicate information about risk and symptoms for gynaecological cancers, including targeted and tailored activity to remove barriers to help-seeking including increasing awareness and widening access to health care.
- Improve access to training and education for healthcare professionals in primary care.
- Consider options for allowing patients to self-refer with gynaecological cancer symptoms.
- Vaccination teams across Wales should continue to deliver the HPV vaccination programme, ensuring hard to reach groups are positively engaged. Focus needs to be put on areas and groups with lower uptake to strengthen programme delivery, increase uptake rates and reduce inequalities.
- Report diagnostic waiting list data for gynaecological cancers routinely, broken down by cancer type, region and other relevant factors to ensure transparency and support identification of challenges in the system.

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<sup>1</sup> Based on the average number of new cases of gynaecological cancer (ICD10 C51-58) diagnosed in Wales in the years 2016-2018.

<sup>2</sup> Based on the average annual European age-standardised incidence rate per 100,000 female population for gynaecological cancer (ICD10 C51-C58) in Wales in the years 2016-2018.

<sup>3</sup> Based on the average annual number of deaths from gynaecological cancer (ICD10 C51-C58) in Wales in the years 2017-2019.

<sup>4</sup> Based on the average annual European age-standardised mortality rate per 100,000 female population for gynaecological cancer (ICD10 C51-C58) in Wales in the years 2017-2019.

<sup>5</sup> Menon, U., Weller, D., Falborg, A.Z. et al. Diagnostic routes and time intervals for ovarian cancer in nine international jurisdictions; findings from the International Cancer Benchmarking Partnership (ICBP). *Br J Cancer* 127, 844–854 (2022). <https://doi.org/10.1038/s41416-022-01844-0>

- Data reported for gynaecological cancers should be disaggregated, to provide information on service provision, helping to understand how well services are performing generally and for specific groups of patients, whether that's people with different types of cancer or different sociodemographic characteristics.

Welsh Government has an opportunity to address wider challenges facing cancer services in Wales in its forthcoming NHS Cancer Services Action Plan, in particular:

- **Funding:** the strategy must be backed up with significant funding to help ensure it delivers the meaningful improvements people affected by cancer deserve, as well as gain the confidence of the cancer community and wider public. Investment is needed to improve patient outcomes and unlock the benefits of innovative approaches and increased efficiency.
- **Action on workforce:** the Welsh Government must set out long-term plans to deliver a sustained expansion of the cancer workforce to meet future demand for cancer services and tackle the chronic shortages in the workforce specialities key to diagnosing and treating cancer. This must be matched with sufficient and sustainable capital funding to ensure diagnostic and treatment capacity is meaningfully expanded across Wales.
- **Better use of data:** data is fundamental to driving our progress against cancer. The Welsh Government should prioritise making improvements in the collection and reporting of datasets to unlock better intelligence and data-driven action in the years to come.

The NHS Cancer Services Action Plan is due to be published in early 2023. Whilst the Plan won't be long-term – we understand it will be for 2023-2026 - it has the potential to be a major milestone for people affected by cancer in Wales, signalling a renewed drive and setting an ambitious roadmap towards better cancer outcomes.

### The information available and awareness about the risk factors for gynaecological cancers across the life course and the symptoms associated with gynaecological cancers.

We are not aware of recent evidence looking at awareness of risk factors and symptoms associated with gynaecological cancers specifically in Wales. Older UK and international studies suggest that awareness of symptoms associated with ovarian cancer is low<sup>6,7</sup>. More recently, a Target Ovarian Cancer report suggests that awareness of some ovarian cancer symptoms is low amongst women in the UK and that some women wrongly believe that cervical screening detects ovarian cancer<sup>8</sup>.

To address this, innovative approaches to communicating information about risk and symptoms should be considered, including, where supported by evidence, targeted and tailored activity to remove barriers to help-seeking including increasing awareness and widening access to health care. This might include identification of opportunities to share

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<sup>6</sup> Brain KE, Smits S, Simon AE, Forbes LJ, Roberts C, Robbé IJ, Steward J, White C, Neal RD, Hanson J; ICBP Module 2 Working Group. Ovarian cancer symptom awareness and anticipated delayed presentation in a population sample. *BMC Cancer*. 2014 Mar 10;14:171. doi: 10.1186/1471-2407-14-171.

<sup>7</sup> Low EL, Waller J, Menon U, Jones A, Reid F, Simon AE. Ovarian cancer symptom awareness and anticipated time to help-seeking for symptoms among UK women. *J Fam Plann Reprod Health Care*. 2013 Jul;39(3):163-71. doi: 10.1136/jfprhc-2012-100473.

<sup>8</sup> Target Ovarian Cancer. *Pathfinder 2022: Faster, Further and Fairer*. Accessed December 2022.

<https://targetovariancancer.org.uk/news/progress-possible-if-urgent-action-taken-now-our-new-research-reveals>

information about cancer risk and symptoms. For example, as part of the Cancer Loyalty Card Study (CLOCS)<sup>9</sup>, researchers are hoping to understand more about public preferences on communication of early signs of ovarian cancer using loyalty card data which may inform recommendations on using supermarket messaging on cancer risk and symptoms. This study is also looking at changes in purchases of relevant items e.g. pain killers and indigestion medication prior to ovarian cancer diagnosis. This study commenced in 2019 and to our knowledge, ended in July 2022 – so we expect results to be published soon. The previous proof of concept study found a unique presence of purchases for pain and indigestion medication prior to ovarian cancer diagnosis, which could signal disease in a larger sample<sup>10</sup>.

### The barriers to securing a diagnosis, such as symptoms being dismissed or confused with other conditions.

There are various barriers to securing a gynaecological cancer diagnosis including:

- Low awareness of risk factors and symptoms associated with gynaecological cancer and difficulties in accessing primary care<sup>11</sup>
- Non-specific symptoms which may be attributed to something else. While some gynaecological cancer symptoms are more specific e.g. abnormal bleeding in endometrial, cervical and vaginal cancers, symptoms of ovarian cancer can be very vague and include abdominal pain, appetite loss, bloating and needing to urinate more often. Evidence suggests these non-specific symptoms have low predictive value for ovarian cancer in primary care.<sup>12</sup>
- (Particularly during the pandemic period), people not wanting to seek help due to concerns about COVID-19 or not wanting to burden the health service<sup>13</sup>

This can result in it taking longer for someone to seek help (patient interval) and/or longer for someone to be referred by their GP (primary care interval). There is some evidence from the International Cancer Benchmarking Partnership (ICBP) to suggest that ovarian cancer patients in Wales do have longer patient intervals and primary care intervals compared to countries with higher survival such as Denmark<sup>14</sup>. Patient intervals and primary care intervals were longer in Wales compared to Denmark (31 days vs 12 days, and 8 days vs 1 day, respectively). This suggests there is scope for improvement in terms of public awareness, help-seeking, access to primary care, access to training and education for healthcare professionals in primary care and timely referrals to secondary care in Wales.

### Accessing primary care

<sup>9</sup> Brewer HR, Hirst Y, Sundar S, et al. Cancer Loyalty Card Study (CLOCS): protocol for an observational case–control study focusing on the patient interval in ovarian cancer diagnosis. *BMJ Open* 2020;10:e037459. doi: 10.1136/bmjopen-2020-037459

<sup>10</sup> Flanagan JM, Skrobanski H, Shi X, Hirst Y. Self-Care Behaviors of Ovarian Cancer Patients Before Their Diagnosis: Proof-of-Concept Study. *JMIR Cancer*. 2019 Jan 17;5(1):e10447. doi: 10.2196/10447.

<sup>11</sup> Pauline Williams, Marie-Claire Rebeiz, Leila Hojeij, Stephen J McCall. *British Journal of General Practice* 2022; 72 (725): e849-e856. DOI: 10.3399/BJGP.2022.0071

<sup>12</sup> Hamilton W, Peters T J, Bankhead C, Sharp D. Risk of ovarian cancer in women with symptoms in primary care: population based case-control study *BMJ* 2009; 339 :b2998 doi:10.1136/bmj.b2998

<sup>13</sup> Quinn-Scoggins HD, Cannings-John R, Moriarty Y, et al. Cancer symptom experience and helpseeking behaviour during the COVID-19 pandemic in the UK: a cross-sectional population survey. *BMJ Open* 2021;11:e053095. doi:10.1136/bmjopen-2021-053095

<sup>14</sup> Menon, U., Weller, D., Falborg, A.Z. et al. Diagnostic routes and time intervals for ovarian cancer in nine international jurisdictions; findings from the International Cancer Benchmarking Partnership (ICBP). *Br J Cancer* 127, 844–854 (2022). <https://doi.org/10.1038/s41416-022-01844-0>

The difficulties in getting an appointment in primary care are well documented, highlighting significant capacity issues in health services that need to be addressed. Other nations in the UK are considering different interventions to widen access including self-referral routes, pharmacy referrals and remote consultations. It is important that the opportunity for innovation in this space is also considered in Wales, sharing with, and learning from other UK nations where appropriate, and ensuring steps are taken to mitigate against the risk of widening health inequalities for those less likely to engage with particular routes.

### Self-referral

There may also be a role for a self-referral pathway, that is a pathway where people can refer themselves for diagnostic tests without seeing their GP, to support people experiencing possible gynaecological cancer symptoms to access timely further investigation. Some cancer pathways will be more amenable than others; those cancers with red flag symptoms, such as postmenopausal bleeding in some gynaecological cancers, and higher levels of symptom awareness are likely to benefit most. There are different possible approaches to self-referral including symptom awareness campaigns that direct people with certain symptoms to a cancer 'hotline' or to book a test.

Preference for self-referral may vary between different patient groups, and people who are more deprived and younger may be less likely to self-refer. It will be important to consider possible barriers to self-referral for some people and ensure it does not cause inequalities in the diagnosis of gynaecological cancers.

It will also be essential to ensure primary care health-professionals are involved in the development of any self-referral pilots, and areas are alerted to their presence in case questions/issues emerge. We asked GPs in Wales (n=45) whether they think self-referral could be an option for various cancer sites and signs or symptoms<sup>15</sup>. For endometrial cancer, most GPs (78%) reported that self-referral could be an option for people with post-menopausal bleeding or discharge. For cervical cancer, less than half (42%) of GPs reported that self-referral could be an option for people with abnormal vaginal bleeding or discharge.

In a public poll, we asked people how likely or unlikely they would be to consider a self-referral route rather than go to a test following an appointment. Just over two-thirds of the people were likely to self-refer for specialist tests or appointments. Around 1 in 5 people were not likely to self-refer and further research is needed to explore their reasons. Variation was observed across different groups:

- Older people (55+) were more likely to have said they would self-refer compared to all the younger age groups
- Women are more likely to have said they would net likely self-refer when compared to men for both specialist tests and appointments.
- People from the C2DE less likely to have said they would self-refer when compared to those from the ABC1 for both specialist tests and appointments

### Pharmacy

Referrals into primary and secondary care by pharmacists are also of interest. As highly trained health professionals situated in the community closer to people's homes, it is hoped that pharmacists are well placed to spot potential signs and symptoms and will be able to facilitate early cancer diagnosis by directly referring people to primary or secondary care. Pharmacy

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<sup>15</sup> Cancer Research UK GP Omnibus survey (2022) Unpublished findings. Data collected by medeConnect who interview 1000 regionally representative UK GPs online. medeConnect is a division of Doctors.net.uk'

referral pilots are at early stages and robust evaluation is required to answer questions about how this would work in practice, the receptiveness of the public and health professionals, and crucially, to understand the effectiveness of pharmacy referrals with regards to cancer diagnoses, the impact on non-cancer diagnoses and any positive or negative impacts on health inequalities.

### Supporting recognition of potential cancer in primary care

The majority of all cancer patients present symptomatically, and via primary care. Therefore supporting primary care in timely recognition and referral of suspected cancer is crucial.

While our understanding is that awareness and use of the NICE guideline to support recognition and referral of cancer in primary care is good in Wales, new evidence has emerged since this was last updated, including for gynaecological signs and symptoms. In particular, for ovarian cancer, new evidence on the blood test CA125 is available which may support the use of age-specific thresholds for using this test, as well as parallel testing of CA125 with ultrasound. CA125 and ultrasound are tests that can be used in the diagnosis of ovarian cancer and new evidence around their use is already reflected in the Scottish referral guidelines for suspected cancer. This should be part of a wider review of this guidance alongside new evidence on vague symptoms, many of which are associated with gynaecological cancers, gleaned from activity in rapid diagnostic centres (RDCs).

The Wales Interventions and Cancer Knowledge about Early Diagnosis (WICKED) research programme is aiming to improve the quality and consistency of primary care approaches in order to improve timely diagnosis of cancer. This programme has developed an intervention to change primary care health professionals' knowledge, attitudes and clinical behaviour with the intention of reducing primary care intervals and improving cancer outcomes. This intervention – ThinkCancer! – involves session for clinical and non-clinical staff, creation of a practice-specific Cancer Safety Netting Plan (CSNP) and the appointment of a Cancer Safety Netting Champion (CSNC) to lead on implementation of the CSNP. Following a recent successful feasibility study, this intervention will be evaluated in a phase randomised controlled trial involving GP practices from across Wales and the North West of England<sup>16</sup>.

### HPV vaccination and access to timely screening services including consideration of the inequalities and barriers that exist in uptake among different groups of women and girls.

A result of years of research carried out across the world, including in Wales, the development and introduction of human papillomavirus (HPV) vaccination to reduce cervical cancer rates has undoubtedly been a success. In the first study of its kind funded by Cancer Research UK, the bivalent Cervarix HPV vaccine was shown to dramatically reduce cervical cancer rates by 87% in women in their 20s who were offered it at age 12 to 13 in England<sup>17</sup>.

Across the UK, the HPV vaccination programme has been disrupted due to school closures during the pandemic, and data on HPV vaccination in Wales from 2021/22 suggests vaccine uptake is not back to pre-pandemic levels. Uptake of dose 1 in year 9 females was 82.1% in

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<sup>16</sup> <http://wicked.bangor.ac.uk/>

<sup>17</sup> Falcaro, M et al. The effects of the national HPV vaccination programme in England, UK, on cervical cancer and grade 3 cervical intraepithelial neoplasia incidence: a register-based observational study. *Lancet*. 2021;398(10316):2084-2092.

2021/22<sup>18</sup> compared to 87.3% in 2019/20<sup>19</sup>. Uptake of dose 2 was also lower in 2021/22 across monitored age groups. Uptake also ranged across Health Board/Local Authority. Unfortunately, Wales do not collect and/or report data on HPV vaccination and ethnicity/deprivation. However, some research suggests that uptake of vaccination in the catch-up cohort was lower in women living in more deprived areas in Wales<sup>20</sup>. Uptake of cervical screening was also lower in this group.

Vaccination teams across Wales should continue to deliver the HPV vaccination programme, ensuring hard to reach groups are positively engaged. Particular focus needs to be put on areas and groups with lower uptake to strengthen programme delivery, increase uptake rates and reduce inequalities. To facilitate this, data on uptake by deprivation quintile and wherever possible, ethnicity should be collected and reported on.

The Screening Division Inequities Report 2020-21 (Screening Division of Public Health Wales) reports that cervical cancer screening coverage is now just below the minimum service standard of coverage (70%), at 69.5% (as of October 2021)<sup>21</sup>. This is a decline from 73.2% reported in 2019/20. There is geographical variation in coverage across Health Boards, the lowest in Hywel Dda University Health Board at 67.7% and highest in Powys Teaching Health Board at 72.7%. Further, coverage was highest in the least deprived areas at 75.4% and lowest in the most deprived areas at 63.3%, a trend observed across all Health Boards. In terms of age, coverage is lowest in the youngest age group (25-29 years) across Wales, at 63.4%; the trend for lower uptake in younger age groups is seen across all Health Boards.

Evidence on existing inequalities in cervical cancer screening coverage in Wales suggest the need to target support in accessing screening services at certain groups, particularly younger people (25-29 years) and those living in the most deprived areas. Therefore, we support the cervical screening recommendations within the Women's Health Quality Statement for:

- Co-production and implementation of targeted interventions to engage with women who are in those demographics least likely to attend cervical screening or access sexual and reproductive services.
- Work underway to increase uptake of cervical screening and follow-up procedures to ensure the effectiveness of the cervical screening programme, saving as many lives as possible from cervical cancer.
- Information and signposting to sources of support following diagnosis of cell-changes after cervical screening.

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<sup>18</sup> Public Health Wales. 2022. Vaccine Uptake in Children in Wales COVER Annual Report 2022. Accessed December 2022 via <https://phw.nhs.wales/topics/immunisation-and-vaccines/cover-national-childhood-immunisation-uptake-data/cover-archive-folder/annual-reports/vaccine-uptake-in-children-in-wales-cover-annual-report-2022/>

<sup>19</sup> Public Health Wales. 2020. Vaccine Uptake in Children in Wales COVER Annual Report 2020. Accessed December 2022 via <https://phw.nhs.wales/topics/immunisation-and-vaccines/cover-national-childhood-immunisation-uptake-data/cover-archive-folder/annual-reports/vaccine-uptake-in-children-in-wales-cover-annual-report-2020/>

<sup>20</sup> Beer H, Hibbitts S, Brophy S, Rahman MA, Waller J, Paranjothy S. Does the HPV vaccination programme have implications for cervical screening programmes in the UK? *Vaccine*. 2014 Apr 1;32(16):1828-33. doi: 10.1016/j.vaccine.2014.01.087

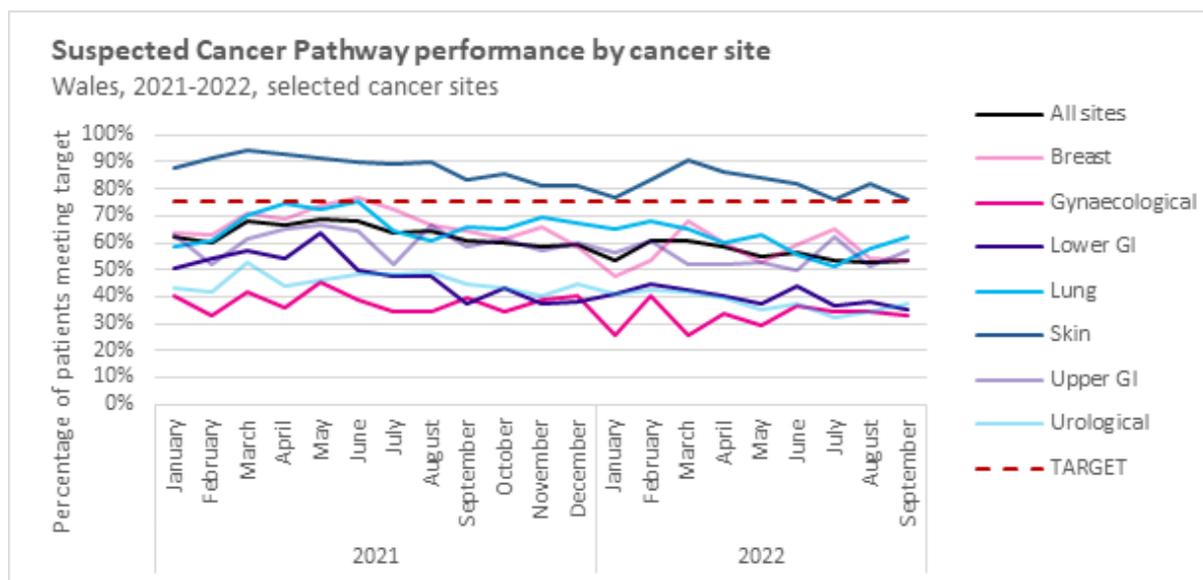
<sup>21</sup> Screening Division Inequalities Report 2020-21. Screening Division of Public Health Wales. June 2022. <https://phw.nhs.wales/news/men-younger-people-and-those-living-in-the-more-deprived-communities-in-wales-show-lower-uptake-of-life-saving-screening-services1/screening-division-inequities-report-2020-21/>

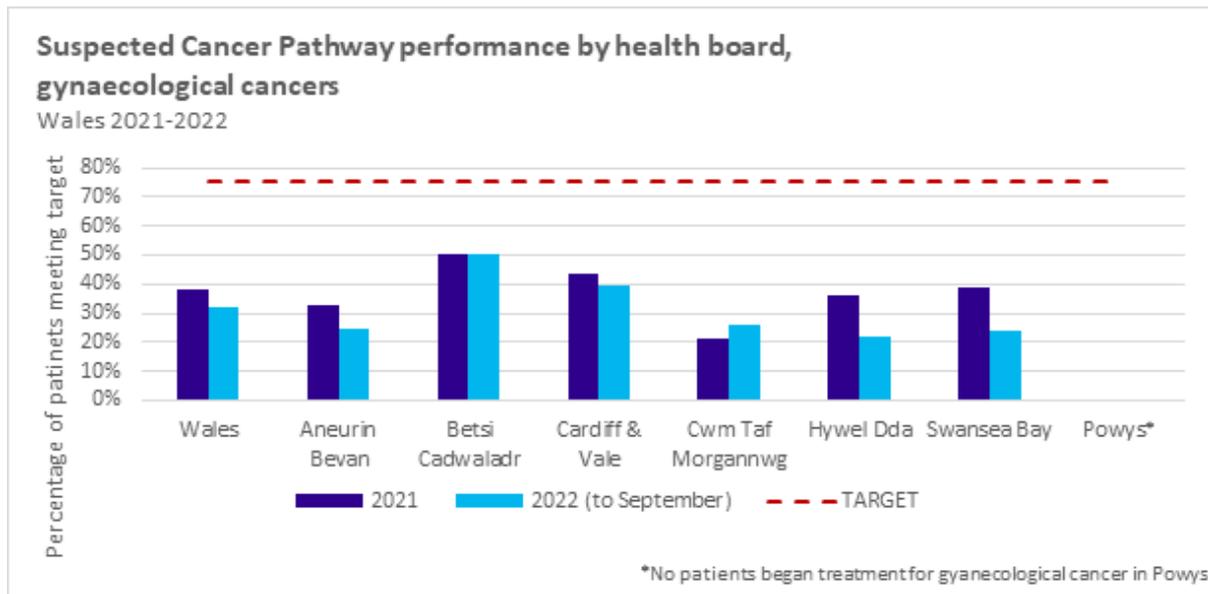
**The prioritisation of pathways for gynaecological cancers as part of NHSE recovery, including how gynaecological cancer waiting lists compare to other cancers and other specialities**

We do not have access to diagnostic waiting list data specifically for gynaecological cancers and therefore cannot make any comparison to the size of the waiting list to that for other cancers or other specialities. Cancer Research UK would like to see routine reporting of this data, broken down by cancer type, region and other relevant factors to ensure transparency and support identification of challenges in the system.

**Whether there are local disparities in gynaecological cancer backlogs (addressing inequalities so that access to gynaecological cancer care and treatment is not dependent on where women live).**

As noted in the introduction to this inquiry, performance against the single cancer pathway for gynaecological cancers is poor, likely a result of long-standing pressures on the health system, exacerbated by the pandemic, and an increase in demand as people are encouraged to present. The graph below shows performance by pathway from January 2021 up to September 2022, highlighting that performance is among the worst for the gynaecological pathway and significantly below the single cancer pathway target of 75%. The second graph below highlights variation in the performance on this pathway between health boards, with most having declined performance in 2022 (to September) compared to 2021.





The Quality Statement for Cancer which describes what good quality cancer services should look like highlights the importance of fully embedded nationally optimised pathways including those for cervical, ovarian, endometrial and vulval cancers<sup>22</sup>. It is important that the implementation of these pathways is evaluated, and performance regularly monitored to ensure they are fully embedded to support planning and help reduce variation. Consideration should also be given to the role of audit and quality improvement efforts to support performance of the ovarian cancer pathway and reduce variation, including the forthcoming national clinical audit on ovarian cancer.

As a follow-up to the Quality Statement, the NHS Cancer Services Action Plan is due to be published in early 2023. This presents an opportunity to build on the principles laid out in the Quality Statement, to invest in the workforce and equipment required address long-waiting times and build sustainable services for the future.

**The extent to which data is disaggregated by cancer type (as opposed to pooling all gynaecological cancers together) and by other characteristics such as ethnicity.**

Currently in Wales data is publicly reported for all gynaecological cancers together and is not disaggregated to individual cancer types despite different gynaecological cancers having different pathways. This makes it challenging to understand poor performance in measures such as cancer waiting times where it is unclear whether one type of gynaecological cancer is driving poor performance or if there are wider system pressures for gynaecological pathways, including beyond cancer. In addition, demographic breakdowns are only available for age and sex.

Cancer Research UK would like to see disaggregated data routinely reported to provide invaluable information on service provision. This will provide transparency, help to understand how well services are performing generally and for different groups of patients, and support the identification, implementation and evaluation of service improvements, helping to ensure equitable access to timely, quality care.

**Whether adequate priority is given to gynaecological cancers in the forthcoming Welsh Government/NHS Wales action plans on women and girls' health and cancer, including**

<sup>22</sup> Welsh Government. The quality statement for cancer. Last updated May 2022. Accessed December 2022.

**details of who is responsible for the leadership and innovation needed to improve cancer survival rates for women.**

With the exception of cervical cancer screening, gynaecological cancers are not specifically mentioned in recent reports outlining quality standards for women's health in Wales, noted below. We do not know whether this will be reflected in the forthcoming plan for women's and girls' health.

This is in contrast to the Women's Health Strategy for England which highlights gynaecological cancers as the 7<sup>th</sup> most popular topic for inclusion and commits to several relevant actions including raising awareness, accelerating control of cervical cancer through HPV vaccination, making improvements to cervical screening (self-sampling, replacing call-recall system), introducing a best practice timed pathway for gynaecological cancers and a national clinical audit for ovarian cancer and funding research into barriers to early diagnosis of uterine cancer. It should be noted that several of these actions should also benefit women in Wales e.g. learning from evaluation self-sampling for cervical screening, research into barriers to early diagnosis, national clinical audit which will include Welsh patients. It will be important for Wales to ensure that any lessons learned from activity elsewhere are taken on board should these approaches also be implemented in Wales.

The Quality Statement for women and girls' health published by Welsh Government in July 2022 outlines expectations for health boards with regards to good quality health services for women and girls. Within this, cancer screening and diagnosis is listed as a condition where there is gender inequality and a need for gender competent services that women might require differently to men. However gynaecological cancers are not specifically mentioned.

Similarly, the 2022 Women's Health Wales quality statement published by the Women's Health Wales coalition, a coalition of patient advocates, condition-specific charities, UK-wide umbrella organisations and Royal Colleges, makes recommendations around the themes of equity, safety, effectiveness, efficiency, timeliness and person-centred care. This includes recommendations specific to cervical screening and cell changes noted above.

From the drafts we have seen through the Wales Cancer Alliance, gynaecological cancers will not be a specific focus on the forthcoming Wales NHS Cancer Services Action Plan – in line with the treatment of other cancer types within the plan. With regards to the leadership needed to drive innovation and improvement of outcomes, research from the International Cancer Benchmarking Partnership (ICBP) highlighted several aspects of leadership perceived as being important for improving outcomes by key informants across the ICBP jurisdictions<sup>23</sup>.

This research found political will to be important in providing a strong mandate to those leading cancer care and the role of central bodies or agencies was described as 'pivotal' in relation to long-term follow through of plans and strategies, alongside clinical and health service leadership to drive implementation. The need for a 'coherent vision' from leaders at different levels of the system was also noted.

**The extent to which gynaecological cancers, and their causes and treatments (including side-effects), are under-researched; and the action needed to speed up health research and medical breakthroughs in diagnosing and treating gynaecological cancers.**

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<sup>23</sup> Morris M, Seguin M, Landon S, McKee M, Nolte E. Exploring the Role of Leadership in Facilitating Change to Improve Cancer Survival: An Analysis of Experiences in Seven High Income Countries in the International Cancer Benchmarking Partnership (ICBP). *Int J Health Policy Manag.* 2021 Aug 4. doi: 10.34172/ijhpm.2021.84.

In 2021/22 Cancer Research UK spent £388million on new and ongoing research including £9m on ovarian cancer focused research and £1m each on cervical and endometrial cancer focused research. Some of this research is being carried out in Wales, for example a study looking for biomarkers of ovarian cancer led by Dr Lavinia Margarit in Swansea<sup>24</sup> and other studies involving patients in Wales e.g. the ROCKeTS study which is looking at the use of existing tests to improve ovarian cancer diagnosis<sup>25</sup>.

Research across the pathway will be crucial for improving gynaecological cancer outcomes, including research to support earlier detection and diagnosis. However, as has been the case right across the UK, capacity to deliver clinical cancer research in Wales has been a long-standing problem, hampering the ability to innovate and improve cancer outcomes. Issues that stem from years of underfunding and limited support<sup>26</sup>. For instance, during a survey of our research community last year, we found that scarcity of dedicated research time<sup>27 28</sup> was the most common barrier to research in the NHS<sup>29</sup>. Even in Health Boards and Trusts considered research-active, 51% of NHS staff reported having insufficient access to research time.

For prospective researchers, the lack of dedicated time makes it harder to start getting involved in research; and for established researchers, the lack of time forces many to self-fund their research (e.g., by using annual leave)<sup>30</sup>, which disincentivises them from staying in research and developing their expertise and experience. By limiting the develop of new researchers and underutilising the abilities of experienced researchers, this therefore restricts the NHS' capacity to conduct clinical research and its ability to expand that capacity.

Fortunately, clinical research's role in developing treatments and vaccines for COVID-19, including high-profile studies like RECOVERY, galvanised public and political enthusiasm for research. One of the outcomes of this has been a 10-year cross-UK Government strategy that aims "to create a world-leading clinical research environment" in the UK<sup>31</sup>. This strategy far from guarantees progress, though - as evidenced by the ongoing issues facing patient recruitment and study set-up.

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<sup>24</sup> <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-study-looking-for-biomarkers-of-ovarian-cancer#undefined>

<sup>25</sup> <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-study-looking-at-current-tests-for-ovarian-cancer-to-help-improve-diagnosis-rockets#undefined>

<sup>26</sup> Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via [https://www.cancerresearchuk.org/sites/default/files/creating\\_time\\_for\\_research\\_february\\_2021\\_-\\_full\\_report-v2.pdf](https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf).

<sup>27</sup> Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via [https://www.cancerresearchuk.org/sites/default/files/creating\\_time\\_for\\_research\\_february\\_2021\\_-\\_full\\_report-v2.pdf](https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf).

<sup>28</sup> Royal College of Physicians. 2020. Research for all? An analysis of clinical participation in research. Accessed 13 July 2021 via <https://www.rcplondon.ac.uk/projects/outputs/research-all-analysis-clinical-participation-research>., p. 8.

<sup>29</sup> Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via [https://www.cancerresearchuk.org/sites/default/files/creating\\_time\\_for\\_research\\_february\\_2021\\_-\\_full\\_report-v2.pdf](https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf)., p. 30

<sup>30</sup> Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via [https://www.cancerresearchuk.org/sites/default/files/creating\\_time\\_for\\_research\\_february\\_2021\\_-\\_full\\_report-v2.pdf](https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf)., p. 8.

<sup>31</sup> HM Government. 2021. Saving and Improving Lives: The Future of UK Clinical Research Delivery. Accessed 18 October 2021 via <https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery>

And simply recovering to a pre-pandemic 'normal' for cancer research will not be enough if Wales is to achieve world-class cancer outcomes. Instead, the Welsh Government must choose to go beyond recovery by expanding the capacity in Wales to deliver clinical cancer research, transforming how cancer research is delivered, including making it more efficient and equitable, and leveraging Wales' scientific strengths to deliver impactful innovations for cancer<sup>32</sup>.

**The priority given to planning for new innovations (therapy, drugs, tests) that can improve outcomes and survival rates for women.**

There is a huge amount of innovation taking place across the prevention, diagnosis and treatment of cancer, including seeking to improve outcomes for women with gynaecological cancers. For example, there is significant interest in the possibility of using liquid biopsies to support earlier cancer detection. This includes promising, early-stage research investigating the use urine tests to detect endometrial cancer<sup>33</sup>, and research into multi-cancer early detection tests. However, the extent to which these tests will lead to a shift in gynaecological cancer outcomes is unknown, and if these tests do result in a meaningful difference to patients, there will be significant implications for health services.

We know that many innovations are not implemented effectively or equitably, if implemented at all. Effective planning to support swift adoption and implementation of innovations following evaluation is therefore key, particularly where an innovation is likely to be disruptive to existing pathways and services. In order to do this, it is important that the health system understands the innovations coming down the pipeline, when these will be ready for adoption, and how implementation across the health system can be supported to ensure equitable access. Wales should monitor developments in this area closely and should consider strategic opportunities to be a testbed for the rest of the UK.

To drive improvement in gynaecological cancer outcomes, we recommend that consideration is also given to optimal implementation of existing interventions, including sharing of best practice and where appropriate alternative approaches to service configuration. We know for example that research suggests that the significant variation observed between comparable countries in ovarian cancer outcomes is in part driven by provision of suboptimal treatment in the countries with worse outcomes<sup>34,35</sup>. This includes Wales where 3-year survival for patients aged 65-74 with later stage disease, the age and stage at which most patients are diagnosed, is 30% compared to 52% in Norway, the best performing country.

**For more information and any queries on our submission, please contact Katie Till, Public Affairs Manager on**

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<sup>32</sup> Cancer Research UK. Beyond Recovery: The case for transforming UK clinical research. Accessed 10 January 2023 via [https://www.cancerresearchuk.org/sites/default/files/beyond\\_recovery\\_-\\_the\\_case\\_for\\_transforming\\_uk\\_clinical\\_cancer\\_research\\_february\\_2022.pdf](https://www.cancerresearchuk.org/sites/default/files/beyond_recovery_-_the_case_for_transforming_uk_clinical_cancer_research_february_2022.pdf)

<sup>33</sup> O'Flynn, H., Ryan, N.A.J., Narine, N. *et al.* Diagnostic accuracy of cytology for the detection of endometrial cancer in urine and vaginal samples. *Nat Commun* **12**, 952 (2021). <https://doi.org/10.1038/s41467-021-21257-6>

<sup>34</sup> Cabasag CJ, Butler J, Arnold M, Rutherford M, Bardot A, Ferlay J, Morgan E, Møller B, Gavin A, Norell CH, Harrison S, Saint-Jacques N, Eden M, Rous B, Nordin A, Hanna L, Kwon J, Cohen PA, Altman AD, Shack L, Kozie S, Engholm G, De P, Sykes P, Porter G, Ferguson S, Walsh P, Trevithick R, Tervonen H, O'Connell D, Bray F, Soerjomataram I. Exploring variations in ovarian cancer survival by age and stage (ICBP SurvMark-2): A population-based study. *Gynecol Oncol.* 2020 Apr;157(1):234-244. doi: 10.1016/j.ygyno.2019.12.047

<sup>35</sup> Norell CH, Butler J, Farrell R, Altman A, Bentley J, Cabasag CJ, Cohen PA, Fegan S, Fung-Kee-Fung M, Gourley C, Hacker NF, Hanna L, Høgdall CK, Kristensen G, Kwon J, McNally O, Nelson G, Nordin A, O'Donnell D, Schnack T, Sykes PH, Zotow E, Harrison S. Exploring international differences in ovarian cancer treatment: a comparison of clinical practice guidelines and patterns of care. *Int J Gynecol Cancer.* 2020 Nov;30(11):1748-1756. doi: 10.1136/ijgc-2020-001403