

# Health and Social Care Committee

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Meeting Venue:

**Committee Room 1 – Senedd**

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Meeting date:

**Thursday, 15 January 2015**

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Meeting time:

**09.30**

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Cynulliad  
Cenedlaethol  
Cymru

National  
Assembly for  
Wales



For further information please contact:

**Llinos Madeley**

Committee Clerk

0300 200 6565

[SeneddHealth@Assembly.Wales](mailto:SeneddHealth@Assembly.Wales)

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## Agenda

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**1 Introductions, apologies and substitutions (09.30)**

**2 Papers to note (09.30 – 09.35) (Pages 1 – 3)**

**Inquiry into the NHS complaints process: correspondence from the Minister for Health and Social Services (Pages 4 – 5)**

**Follow up inquiry into the contribution of community pharmacy to health services in Wales: correspondence from the Minister for Health and Social Services (Pages 6 – 8)**

**Inquiry into new psychoactive substances (“legal highs”): correspondence from the Minister for Health and Social Services (Pages 9 – 10)**

**The Committee's forward work programme: correspondence from the Children, Young People and Education Committee (Page 11)**

**Scrutiny of the Older People’s Commissioner for Wales: correspondence from the Minister for Health and Social Services (Page 12)**

Correspondence from the Petitions Committee: P-04-570 Inequitable Access to Treatments That Have Not Been Nationally Appraised in NHS Wales (Pages 13 – 17)

**3 Motion under Standing Order 17.42(vi) to resolve to exclude the public from items 4 and 5 of the meeting (09.35)**

**4 Inquiry into alcohol and substance misuse: preparation for engagement activity (09.35 – 09.45) (Pages 18 – 21)**

**5 Follow up on the one-day inquiry into stillbirths in Wales: consideration of evidence (09.45 – 10.00) (Pages 22 – 40)**

[Minister for Health and Social Services' update report](#)

#### [Written evidence](#)

**6 Inquiry into new psychoactive substances (“legal highs”): evidence session 8 (10.00 – 10.45) (Pages 41 – 44)**

Dan Greaves, Head of Drugs & Alcohol Unit, Home Office

Angela Scrutton, Head of Drug Legislation, Home Office

Break (10.45 – 11.00)

**7 Safe Nurse Staffing Levels (Wales) Bill: evidence session 1 (11.00 – 12.15)**

Kirsty Williams AM, Member in Charge

Lisa Salkeld, Legal Services, National Assembly for Wales Commission

Philippa Watkins, Research Service, National Assembly for Wales Commission

[Safe Nurse Staffing Levels \(Wales\) Bill](#)

#### [Explanatory Memorandum](#)

**8 Motion under Standing Order 17.42(vi) to resolve to exclude the public from the remainder of the meeting (12.15)**

**9 Inquiry into new psychoactive substances (“legal highs”): consideration of evidence received (12.15 – 12.30)**

**10 Safe Nurse Staffing Levels (Wales) Bill: consideration of evidence received (12.30 – 12.45)**

## Health and Social Care Committee

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Meeting Venue: **Committee Room 1 – Senedd**

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Meeting date: **Wednesday, 10 December 2014**

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Meeting time: **09.30 – 11.27**

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This meeting can be viewed on [Senedd TV](http://senedd.tv/en/2510) at:  
<http://senedd.tv/en/2510>

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### Concise Minutes:

#### Assembly Members:

David Rees AM (Chair)  
Peter Black AM  
Janet Finch–Saunders AM  
John Griffiths AM  
Elin Jones AM  
Darren Millar AM  
Lynne Neagle AM  
Gwyn R Price AM  
Joyce Watson AM  
Lindsay Whittle AM  
Kirsty Williams AM

#### Committee Staff:

Llinos Madeley (Clerk)  
Helen Finlayson (Second Clerk)  
Sian Giddins (Deputy Clerk)  
Rhys Morgan (Deputy Clerk)  
Gareth Howells (Legal Adviser)  
Stephen Boyce (Researcher)  
Amy Clifton (Researcher)  
Sian Thomas (Researcher)  
Gwyn Griffiths (Legal Adviser)

## Transcript

View the [meeting transcript](#).

### **1 Introductions, apologies and substitutions**

1.1 Apologies were received from Alun Davies. Joyce Watson substituted.

### **2 Papers to note**

2.0a The Committee noted the minutes of the meetings on 20 and 26 November.

2.1 Post-legislative scrutiny of the Mental Health (Wales) Measure 2010:

Correspondence from the Minister for Health and Social Services

2.1a The Committee noted the correspondence from the Minister for Health and Social Services.

### **3 Motion under Standing Orders 17.42(vi) and (ix) to resolve to exclude the public from the remainder of the meeting**

3.1 The motion was agreed.

### **4 Post-legislative scrutiny of the Mental Health (Wales) Measure 2010: consideration of draft report**

4.1 The Committee considered and agreed the draft report, of its post-legislative scrutiny of the Mental Health (Wales) Measure 2010, subject to minor changes.

### **5 The Committee's forward work programme**

5.1 The Committee discussed the forward work programme and agreed to:

- seek a factual briefing from Welsh Government officials on the *Independent Living Fund – future arrangements to support recipients in Wales* consultation;
- write to the Minister for Health and Social Services to seek further information about health finances, in response to the Finance Committee's recommendation in its report on the Welsh Government's 2015–16 draft budget that the Health and Social Care Committee should undertake a piece of work on health reform; and
- undertake a short and focused piece of work on the GP workforce in Wales.

### **6 Inquiry into new psychoactive substances (“legal highs”): consideration of the key issues**

6.1 The Committee discussed and agreed the key issues that have arisen during the Committee's inquiry into new psychoactive substances (“legal highs”).

6.2 The Committee agreed to extend the inquiry in order to take oral evidence from Home Office officials at its meeting on 15 January 2015.

## **7 Safe Nurse Staffing Levels (Wales) Bill: consideration of approach to Stage 1 scrutiny**

7.1 The Chair welcomed Peter Black who will be substituting for Kirsty Williams for business relating to the Committee's Stage 1 scrutiny of the Safe Nurse Staffing Levels (Wales) Bill.

7.2 The Committee considered and agreed its approach to Stage 1 scrutiny of the Bill.

# Agenda Item 2.1

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: MB/MD/5414/14

David Rees AM  
Chair  
Health and Social Care Committee  
National Assembly for Wales  
Cardiff Bay

[HSCCommittee@wales.gov.uk](mailto:HSCCommittee@wales.gov.uk)

6 January 2015

Dear David,

## The NHS Complaints Process in Wales

I write further to your letter of 2 December requesting further information for the Health and Social Care Committee about the timescales for the delivery of a number of pieces of work.

You specifically requested information on the following:

The pilots of iWantGreatCare, currently underway in Wrexham Maelor Hospital and the Princess of Wales Hospital, Bridgend are due to be completed by mid February 2015. An evaluation of the pilot schemes will then follow. Both Abertawe Bro Morgannwg University Health Board and Betsi Cadwaladr University Health Board have published information based on the feedback received from patients during the pilot. The feedback so far, which is openly available through the iWantGreatCare website, is showing overall positive reactions from patients and their families.

The work of the subgroups of the National Quality and Safety Forum is well underway. It is planned that this work will be drawn together for consideration by the Forum at its meeting in April 2015. This process will enable any potential changes required to The National Health Service (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011 to be identified. Any possible amendments to the regulations would be subject to public consultation.


The Community Health Councils are also fully engaged in this process. Work is already well underway on the development of a formal protocol to improve liaison and joint working with Healthcare Inspectorate Wales, involving the exchange of intelligence on NHS services including complaints. This will provide the basis for a more structured approach to joint working between the organisations. In addition the proposals to amend the Regulations set out in the current CHC consultation exercise, to give the Board of CHCs the power to set standards are relevant in this context. It is envisaged such a standard would be developed in relation to the operation of the Independent Advocacy Service.

The Evans Review cited a number of areas which he felt would benefit from taking a national approach. In my written statement I outlined the need for further work to be undertaken to determine this. It will become clearer as the work progresses and proposals are developed, whether any future changes might not be possible under the current legislative framework and may need new legislation.

I will publish further updates about the work in due course.

I hope this information is helpful to the Committee.

Yours sincerely,

A handwritten signature in black ink that reads "Mark Drakeford". The signature is written in a cursive, slightly slanted style.

**Mark Drakeford AC / AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



# Agenda Item 2.2

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: MB/MD/5257/14

David Rees AM  
Chair  
Health and Social Care Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

9 December 2014

Dear David,

Thank you for your letter of 5 November presenting the Committee's conclusions from the follow up inquiry into the contribution of community pharmacy to health services in Wales.

For ease of reference I have followed the structure of the annex to your letter in providing you with my further comments.

## **Recommendation 1 – Communication mechanisms to inform the general public about pharmacy services**

I am pleased the Committee acknowledges the progress made to date to ensure a good standard of consistent and comprehensive information is available to the public about community pharmacy services. As I stated in my evidence to Committee, I envisage standardised, bi-lingual service information being established in community pharmacies across Wales in early 2015.

I agree we should harness the positive outcome of closer working between GPs and community pharmacists through the Choose Pharmacy pathfinder service. The evaluation results of the service will help to identify how to translate that across into general partnership working.

One of the key drivers for securing inter professional co-ordination is the primary care clusters. The national plan for primary care "*Our plan for a primary care service for Wales up to 2018*" was published the day after the Committee published its follow up report. The plan highlights the pivotal role of GPs and reinforces the importance of fostering collaboration to co-ordinate access to the wide range of services required within a local community to help meet their health and well-being needs.

## **Recommendation 2 – Providing a clear national lead for the future development of community pharmacy services**

The Committee's comments are noted.

Bae Caerdydd • Cardiff Bay  
Caerdydd • Cardiff  
CF99 1NA

English Enquiry Line 0845 010 3300  
Llinell Ymholiadau Cymraeg 0845 010 4400  
Correspondence: Mark.Drakeford@wales.gsi.gov.uk  
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### **Recommendation 3 – Transition to capitation-based payments, underpinned by a patient registration system**

Remuneration on a capitation basis can facilitate options for treating people holistically, build up long term relationships and allow contractors to better understand patient needs and their medical history. They may also make way to reduce an emphasis on volumes and enhance mechanisms for providing additional service improvements.

Capitation payments are currently being used for the Choose Pharmacy service and we will consider a wider application in light of the evaluation findings with contractors and their representative bodies.

### **Recommendation 4 – Promotion of further enhanced services with a national specification for community pharmacy**

All Welsh Government policy relating to the introduction of new services is underpinned by a robust evidence base.

The three-year medium term plans being developed by health boards for 2015-18 will reflect the framework provided by Welsh Government which requires a shift in focus and resources towards primary care and community services and to incorporate improved mechanisms for preventing and managing chronic conditions by improving planning processes and setting out service improvement priorities.

I can confirm that health board plans will not be approved unless there are assurances that these changes will be delivered at the required scale and pace. In addition, the primary care clusters will, as they mature, provide a means of understanding the skills offered by workforce members and a means of providing a shift in the balance of care for chronic conditions towards community care and nearer to home.

The medicines use and hospital medicines discharge reviews continue to support patients with particular needs and the management of chronic conditions. Officials are in discussion with Community Pharmacy Wales to increase the proportion of Medicine Use Reviews undertaken within target groups to bolster this service.

I have already confirmed to you in my letter of 15 November 2014 that Public Health Wales, in conjunction with health boards, is currently reviewing the smoking cessation service it provides and recommendations will be made by the end of January 2015.

### **Recommendation 5 – Consistent participation of community pharmacies in public health campaigns**

During this third year of a national community pharmacy NHS influenza service, I am pleased that participation has increased again. The end of November 2014 data shows that 230 pharmacies have provided vaccinations under the scheme, up from 195 the previous year. The number of vaccinations being provided by pharmacies has also increased with over 9,000 having been administered so far this year.

### **Recommendation 6 – Cooperation and joint working between community pharmacists and GPs**

I am not convinced establishing a national working group is the most effective way of promoting closer collaboration between GPs and community pharmacists. I believe, the greatest progress will be made on closer working when professionals are engaged on a common agenda, such as the Choose Pharmacy pathfinders which have successfully built good inter professional relationships.

The primary care cluster developments will have a strong focus on the further development of professional networks and partnerships and will require GPs to engage more with the wide range of health and social care professionals, including community pharmacists. This will directly improve the coordination, quality and integration of health and social care planning at a local level and offers a real opportunity for a breakthrough in locally-led service planning and delivery. I want to extend locality groups to include community pharmacy and I expect to see this aspiration reflected in health board plans for 2015.

### **Recommendation 7 – Access to summary patient records**

The Committee's comments are noted. I can confirm the ultimate aim of the current development work is to scope and test the IT and information sharing protocols to enable the sharing of relevant patient information between GPs, hospitals and all community pharmacists for all community pharmacy services in the future.

*Best wishes,*

*Mark.*

**Mark Drakeford AC / AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Ein cyf/Our ref: MB/MD/5375/14

Darren Millar AM  
The National Assembly for Wales  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

15 December 2014

Dear Darren,

**Health and Social Care Committee – 26 November 2014  
Cost of healthcare at the new prison, Wrexham**

As part of the questions raised within the Health and Social Care Committee, you asked about funding for the delivery of substance misuse services within the new prison, being built in Wrexham. The wider context of this question related to the funding provision for health and social care given these are devolved matters and the need to secure appropriate resources from the Ministry of Justice, which has commissioned this facility, in order to deliver the necessary services.

I can confirm that in order to secure an equitable settlement, I have written to the Parliamentary Under Secretary of State for Justice setting out the Welsh Government's expectation that negotiations will commence formally early in the New Year. My officials, those of Betsi Cadwaldr University Health Board and the local authority have already started work on the detailed analysis necessary to agree a sustainable financial cost model. After taking responsibility for health care in public sector prisons it is fair to say we have a better understanding of the full costs. No final figure is agreed as yet and certainly not the level of individual issues such as substance misuse services. For comparison HMP Cardiff has a resident offender population of 811 and I am informed by the health board there is a budget of £2.3m to meet the health needs of this population. However, it must also be noted that the 'churn' of the prison population in Cardiff is 4,403, which may have a greater impact on healthcare need at any given time. So a direct comparison with other prisons that may have higher or lower rates may not be necessarily appropriate.

I am determined to ensure resources are secured to deliver all aspects of healthcare, including for those with substance misuse problems and related matters.

I am copying this to David Rees AM, chair of the Committee and the Minister for Public Services Leighton Andrews AM.

Best wishes

Mark Drakeford

**Mark Drakeford AC / AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



**David Rees AM  
Chair  
Health and Social Care Committee  
National Assembly for Wales**

**Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff  
CF99 1NA**

**15 December 2014**

**Dear David**

**Thank you for your letter dated 2 December. As you are aware the Committee has just published their report on CAMHS and has already agreed do some further work in this area specifically on prescription drugs and referral rates.**

**The timing of this work is uncertain at the moment as the Committee has just started considering the Qualifications Wales Bill and has agreed to conduct its next policy inquiry into supply teachers.**

**Therefore is unlikely the Committee will have the capacity to undertake a piece of work on the Welsh Government's Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales before the end of this Assembly.**

**Yours Sincerely**

**Ann Jones AC / AM  
Cadeirydd / Chair**

# Agenda Item 2.5

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: MB/MD/4836/14

David Rees AM  
Chair, Health and Social Care Committee  
Cardiff Bay  
CF99 1NA

[SeneddHealth@Assembly.Wales](mailto:SeneddHealth@Assembly.Wales)

Cc: Sarah Rochira, Older People's Commissioner for Wales  
[Sarah.Rochira@olderpeoplewales.com](mailto:Sarah.Rochira@olderpeoplewales.com)

8 January 2015

Dear David,

Thank you for your letter dated 2 December 2014, in which you express the Health and Social Care Committee's support for "A Place to call home", the Older People's Commissioner's review and recommendations.

Officials are currently working on a formal response to the report and as agreed with the Older People's Commissioner, it will be submitted on the 9 February 2015. A copy of the response will of course be shared with you at that point.

Best wishes,

Mark

**Mark Drakeford AC / AM**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Y Pwyllgor Deisebau  
Petitions Committee

David Rees AM  
Chair of the Health and Social Care  
Committee  
Ty Hywel  
Cardiff Bay  
CF99 1NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff  
CF99 1NA

Our ref: P-04-570

December 2014

Dear *David*

The Petitions Committee is currently considering the following petition from Genetic Alliance UK, Tuberous Sclerosis Association, Association of Glycogen Storage Disorders, which has collected 1089 Signatures.

### **P-04-570 Inequitable Access to Treatments That Have Not Been Nationally Appraised in NHS Wales**

*We the undersigned call on the National Assembly for Wales to review the use of the "exceptionality rule" in determining whether a patient can access a treatment through the Individual Patient Funding Request process.*

***Additional Information:** To access treatments through the IPFR process, a patient population must demonstrate its exceptionality. For common illnesses, it may be possible to identify a subset of patients within the larger population who are more likely to respond to a particular therapy. For rare disease patients, demonstrating that you are a unique patient when you are part of a small group of patients whose condition is considered rare is practically impossible. The exceptionality criteria place an onus on clinicians to provide evidence that the patient's clinical condition is significantly different to the general population of patients with the same condition and is likely to gain significantly more benefit from the intervention than might normally be expected. This evidence requirement is too onerous to apply to patients with rare diseases due to small patient numbers within rare disease*

Bae Caerdydd / Cardiff Bay  
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*populations. Patients with great clinical need are prevented from accessing life-changing/ life-saving treatments.*

At our meeting on 11 November, the Committee considered correspondence from the Minister for Health and Social Services and the Petitioner. I attach copies of this correspondence for your information.

We agreed to draw the petition to the attention of the Health and Social Care Committee and ask whether you would be prepared to consider carrying out an inquiry as requested by the petitioners.

I would be grateful if you could draw this letter to the attention of the Committee and let me know their views.

Yours sincerely



**William Powell AC / AM**  
Cadeirydd / Chair

Enclosures:

Correspondence from the Minister for Health and Social Services dated 31 August 2014; and  
Correspondence from the Petitioner dated 5 November 2014.

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



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Eich cyf/Your ref P-04-570  
Ein cyf/Our ref MD/03174/14

William Powell AM  
Assembly Member for Mid & West Wales  
Chair Petitions Committee  
Ty Hywel  
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31 August 2014

*Dear William,*

Thank you for your letter of 14 August on behalf of the Petitions Committee, regarding Petition P-04-570 - Inequitable access to treatments that have not been nationally appraised in NHS Wales.

As you are aware, I announced a review of the IPFR process on 16 October last year. The review group produced a report which concluded the current IPFR process in Wales supports rational, evidence based decision making for those treatments which are not routinely available. They also made a number of recommendations aimed at strengthening the process. On 30 April 2014 I issued a Cabinet Written Statement regarding access to medicines, including the recent IPFR review, which can be accessed at:

<http://wales.gov.uk/about/cabinet/cabinetstatements/2014/?lang=en>

The Written Statement also announced we will have a new appraisal system specifically tailored to address those medicines that treat rare diseases; often referred to as orphan and ultra orphan medicines. I will be issuing a further statement on access to new medicines in September.

I hope this information is helpful and clarifies the current position.

*Best wishes,  
Mark.*

**Mark Drakeford AC / AM**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

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Mr William Powell AM  
Assembly Member for Mid and West Wales  
Chair Petitions Committee  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

05 November 2014

Dear Mr Powell,

[Response to letter from the Minister for Health and Social Services regarding the Petition P-04-570 – Inequitable access to treatments that have not been nationally appraised in NHS Wales](#)

In his letter dated 31<sup>st</sup> August 2014, the Minister for Health and Social Services, Mark Drakeford, outlined his response to a petition supported by Genetic Alliance UK, Tuberous Sclerosis Association and Association of Glycogen Storage Diseases, and signed by over 1,000 individuals and patients which called for a review into the use of the 'exceptionality' criterion when determining whether a patient with a rare condition is able to access a treatment through the Individual Patient Funding Request (IPFR) process.

In his response, the Minister referred to the recent review of this process by the National IPFR Review Group in October 2014. The remit of that review did not include a consideration of the appropriateness of the exceptionality criterion, and instead focused on improving the transparency and consistency of the process. Genetic Alliance UK sat as a member of that review group and at no point was the appropriateness of the exceptionality criterion to IPFR applications from rare disease patients discussed or considered.

While we accept that the IPFR process is not designed as a means through which rare disease patients can access the medicines their clinician's agree they need, due to a lack of alternative options this route is the only one available to them. The exceptionality criterion is a barrier that prevents them from being able to take these medicines as a result of deficiencies within the rest of the system.

As our petition states, a review of the current IPFR criteria by the Health and Social Care Committee, including an investigation into the use of the exceptionality criterion when considering IPFR applications from patients affected by rare conditions, is necessary to finally address this issue.

Yours sincerely,

Alastair Kent OBE, Director of Genetic Alliance UK and Chair of Rare Disease UK

Registered charity numbers: 1114195 and SC039299  
Registered company number: 05772999

### Why are so many patients with rare conditions making IPFR requests?

Currently, many rare disease medicines have not been through a national health technology appraisal. As Genetic Alliance UK's recent work revealed, this is a particular issue for patients affected by rare conditions because the National Institute for Health and Care Excellence (NICE) has historically appraised very few rare disease medicines: less than 10% of the 47 rare disease medicines launched between 2002 and 2013 for the treatment of non-cancer indications were appraised by NICE<sup>1</sup>. This is unlikely to change in the future as NICE's new process for appraising highly specialised technologies only has capacity to appraise three medicines a year<sup>2</sup>. The duty of evaluation of the vast majority of medicines for rare diseases will pass to AWMSG in Wales.

As a result of these factors, no national commissioning policy exists for many rare disease medicines and so patients in Wales currently have no alternative but to try to access potentially life changing medicines through the IPFR process.

In this context, it is clear how the 'exceptionality' criterion creates a barrier to medicine access for patients with rare conditions as in many cases it is a whole group of patients who are applying for access to a treatment and, by definition, do not differ from each other. In these cases it is the whole patient population that could benefit and a thorough appraisal of the evidence would be ideal. The urgency of the medical need and the risk of avoidable progression is great and therefore waiting for such an appraisal to be carried out is not an option.

### Why do patients with rare diseases believe that the 'exceptionality' criterion is not appropriate?

The report published by the IPFR Review Group defines the term 'clinical exceptionality' as: 'the patient's clinical condition is significantly different to the general population of patients with the same condition and as a result, the patient is likely to gain significantly more benefit from the intervention than might normally be expected.'

Aside from the fact that in the absence of any commissioning policy the exceptionality criterion becomes a barrier to cohorts of patients accessing a treatment through the IPFR process as a last resort, there are two additional reasons why this criterion can disadvantage patients with rare conditions seeking to access medicines through IPFRs:

1. Rare diseases often vary in the nature and severity of the associated symptoms. It is therefore difficult to identify one patient as 'exceptional'.
2. The patient population affected by a single rare condition is small. As a result there can be little information about the natural history of the condition and/or limited evidence available. It can be difficult to prove that one patient is different from a population about which little is known.

**Genetic Alliance UK** is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all who need them. We actively support research and innovation across the field of genetic medicine.

**Rare Disease UK** is a multi-stakeholder campaign run by Genetic Alliance UK, working towards the delivery and implementation of the UK Strategy for Rare Diseases, which was published by the Department of Health in November 2013.

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<sup>1</sup> Genetic Alliance UK's Patient Charter on NHS England's commissioning of medicines for rare conditions (October 2014)  
Accessed here: [www.geneticalliance.org.uk/docs/hst-patient-charter\\_final.pdf](http://www.geneticalliance.org.uk/docs/hst-patient-charter_final.pdf)

<sup>2</sup> Genetic Alliance UK's Patient Charter on NICE's Highly Specialised Technology Evaluation Programme (April 2014)  
Accessed here: [www.geneticalliance.org.uk/docs/hst-patient-charter\\_final.pdf](http://www.geneticalliance.org.uk/docs/hst-patient-charter_final.pdf)

# Agenda Item 4

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

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# Agenda Item 5

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

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