

[National Assembly for Wales](#)

[Health and Social Care Committee](#)

[The work of the Healthcare Inspectorate Wales](#)

Evidence from Genetic Alliance UK – HIW 16

Consultation response

Inquiry into the work of Healthcare Inspectorate Wales

Response from Genetic Alliance UK, 20th September 2013

Introduction

1. Genetic Alliance UK is the national charity supporting all those affected by genetic conditions. We aim to improve the lives of people affected by genetic conditions by ensuring that high quality services and information is available to all who need them. Our membership represents more than 160 voluntary organisations working for a wide range of conditions, many of which pose complex health and social care needs.
2. In 2008 Genetic Alliance UK launched Rare Disease UK (RDUK), the national multi-stakeholder alliance for people with rare diseases and all who support them. RDUK is campaigning for a National Plan for Rare Diseases in the UK, so that patients and families living with rare conditions have equitable access to effective services.
3. We welcome the opportunity to respond to this enquiry.

Role of Healthcare Inspectorate Wales in strengthening the patient voice

4. Healthcare Inspectorate Wales (HIW) is the independent inspectorate and regulator for all healthcare in Wales. The role of HIW in strengthening the voice of patients in the way health services are reviewed is particularly important for patients and their families in Wales who are affected by a rare disease.
5. A rare disease is defined by the EU as affecting fewer than 5 in 10,000 of the general population.¹ Due to the nature of rare diseases, patient populations of single rare conditions are small. There are however many thousands of rare diseases affecting the European population, estimates vary but most put the figure somewhere between 6,000 and 8,000². Although there are

¹ Council Recommendation on an action in the field of rare diseases, June 2009
Accessed: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF>

² www.eurordis.org/about-rare-diseases and report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=80

no precise figures on the amount of people affected by rare diseases in Wales because this data is not collected, best estimates arising from the Council Recommendation suggest that 1 in 17 people will be affected by a rare disease at some point in their lives. This amounts to 175,000 people in Wales.

6. Currently, there is a broad framework under which HIW operates guided by the Health and Social Care (Community Health and Standards) Act 2003. The remit of the work undertaken by HIW extends to the availability of and access to healthcare as well as the quality and effectiveness of healthcare for patients and the public. As a result of the small cohorts of patients affected by single rare conditions and the fact that many are severe and life-limiting, it is imperative that patients have the opportunity to voice their concerns about availability and access to services in addition to the quality and effectiveness of healthcare services. Due to the complex nature of many rare conditions, patients will require access to specialised services as well as non-specialised services that are commissioned and planned at a local level. Delivering co-ordinated care at designated centres of expertise, where clinicians have a greater understanding of the condition is invaluable for patients.
7. Access to centres of expertise, whether they are based in Wales, England or further afield is vital for patients and the value of specialised services needs to be recognised. For rare disease patients, it is important that the remit of HIW extends to those specialised services that are accessed when patients are referred for diagnosis/treatment outside of Wales. Currently there is wide variation in health services for patients with rare diseases across the UK. This variation is due to decisions taken at different levels of the commissioning or planning structure which result in patients having very different experiences, dependant on the condition they have and where they live.
8. Part of HIW's work aims to involve and engage citizens by seeking views and perspectives on specific aspects of healthcare and working with patients, service users, carers and their families to develop new approaches to its work. There is also a commitment to 'work together with the Third Sector and representative organisations to help ensure that the views of specific service user groups, in particular those who may be seldom reached, inform and influence what we do and how we do it'.³ It is important for mechanisms to be put in place to ensure that HIW work to achieve this commitment to groups that that are seldom reached. This is specifically relevant to those affected by rare conditions as care is often poorly coordinated and fragmented and there is frequently lack of communication between all professionals involved in the care of the patient.
9. It is important for HIW to support the Third Sector in the engagement process as voluntary organisations often have limited resources and funds. Genetic Alliance UK would welcome the opportunity to work with HIW to discuss better ways to develop engagement processes between HIW, patients and Third Sector organisations.
10. Following consultation with a number of patient organisations in Wales, it seems that although the outcome of HIW's work is publicised via their website, it is particularly difficult to find information on how to engage with HIW to contribute and participate in this work. A policy needs to be developed and implemented to ensure that these groups are made aware of the remit of HIW and given the opportunity to actively engage in its work.
11. As mentioned in point 8, the role of HIW in strengthening the voice of the patient is especially important for groups that are seldom reached but extremely vulnerable and dependant on access to health services at both a local and national level. Genetic Alliance UK supports the introduction of a streamlined and open approach to engaging with patients, patient organisations and the

³ Healthcare Inspectorate Wales: 'Engaging and Involving Patients and the Public'
Accessed: <http://www.wales.nhs.uk/sites3/Documents/477/HIW%20PPI%20Statement%20041109-e.pdf>

public. Strengthening their voice will support HIW in reviewing the delivery of health services for the people of Wales.

12. Genetic Alliance UK supports the establishment of a forum of stakeholders including individuals, patient organisations and healthcare professionals who would actively participate in the work of HIW. This forum would work alongside HIW to help the organisation develop a better understanding of what matters most to patients and the public in putting their interests first. HIW has already made a commitment to 'reach out to those who are least likely to be heard and most likely to get ill'.⁴ The establishment of a forum would enable a joined up approach to scrutinising healthcare services; with better communication channels between HIW, patients and the public. Strengthening the relationship between stakeholders and opening communication channels would ensure that the views of patients and the public are heard and built into the early planning stages of healthcare reviews.



Alastair Kent OBE
Director

⁴ Healthcare Inspectorate Wales: 'Engaging and Involving Patients and the Public'
Accessed: <http://www.wales.nhs.uk/sites3/Documents/477/HIW%20PPI%20Statement%20041109-e.pdf>