

The Genetic Interest Group is an umbrella group representing 138 member charities supporting patients and families affected by inherited health conditions. Our member charities represent inherited conditions on a spectrum from common multifactorial conditions such as heart disease to serious single gene conditions that frequently have no cure or treatment available. Patients with these conditions have a wide and varied range of requirements, this response speaks from the common interests of our members.

Question 1: Do you have any general comments about the Common Assessment Framework?

The majority of patients with single gene disorders receive their diagnosis from a Regional Genetics Service (RGS), a tertiary care component of the National Health Service, most commonly accessed through referral from a General Practitioner or Paediatric Services. RGS patient care records are treated with a high degree of confidentiality due to their familial implications: it is possible to infer the health status of parents, children and other relatives of a patient with knowledge of that patient's genetic status. These records are not usually shared with other services within the NHS without explicit consent from the patient/family.

This confidential nature of the health records of the patients we represent presents a problem for a Common Assessment Framework for patients with inherited conditions, particularly regarding the proposal to share this information with organisations outside of the NHS.

This barrier to the implementation of a Common Assessment Framework for patients with genetic conditions is a great pity, as the Genetic Interest Group can see an number of benefits that a CAF system or similar would provide to the patients we represent:

- Patients, as part of the journey towards a diagnosis or coordinated treatment will frequently have to repeat descriptions of their situation to practitioners in different areas of the NHS. Further to this, patients with rare conditions frequently speak from a position of greater knowledge about their condition than members of their healthcare team. Patients such as these would benefit from a method by which their condition could be described in a standardised way, with the purpose of easing communication with specialised care within the NHS.
- Further, patients with complex and/or rare inherited conditions face a similar communication issue when approaching the relevant authorities for provision of social care and benefits. Many patients, though seriously ill, will not yet have a diagnosis, and would greatly benefit from the weight a standardised document similar to the CAF would provide in such discussions.

The Common Assessment Framework aims to provide "a single community based support system focused on the health and well-being of the local population; binding together local Government, primary care, community based health provision, public health, social care and the wider issues of housing, employment, benefits advice and education/training."

Many of the conditions represented by GIG's members are rare or extremely rare. Where treatment is available, specific aspects of it must be provided in specialised centres that serve large geographical areas. This should be integrated with those aspects of their care that can and should be delivered locally. The degree to which the CAF is focused upon local care at a community level without acknowledgement of the role of specialised centres of expertise would seem to be a further barrier for the implementation of CAF for patients and families that many of our members represent.

For the reasons set out above, it is clear that as it is proposed, a CAF would not be entirely appropriate for patients affected by many inherited health conditions; GIG is therefore concerned that the patients affected by such conditions will not be adversely affected by the inability to participate in such a scheme. Though care must be provided a level higher than local community based healthcare, these patients still rely on local support for their social care and/or benefit provision. These authorities should be able to dispense support to patients who don't participate in a CAF scheme to as high a level as they do for those that do participate.

GIG would be happy to enter into a dialogue to discuss these matters further.

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

Alastair Kent
Director