



**CLINICAL GOVERNANCE:  
MEETING THE NEEDS OF PATIENTS  
AND THEIR FAMILIES –  
A PATIENT CENTRED CHECKLIST  
FOR CLINICAL GENETICS**



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Patients, referred to a regional genetic centre, may be anxious and confused. Often they know little or nothing about the reasons that have precipitated their referral, and they may not know what to expect from the service.

The following checklist has been devised from questions which people have asked GIG, from comments made by colleagues and from other sources. It is intended to highlight those questions which frame themselves in patient's minds, which may remain unuttered, but which, if they were and the answers were positive, then it is likely that the patient would be receiving a quality service. It has been developed for use by those providing clinical genetics services as a tool for measuring performance, and for commissioners as an indicator of appropriate quality standards and as a framework for establishing the resource needs of clinical genetics services.

The list is by no means exhaustive. Additions, improvements and amendments are welcome at any stage! Nor is the order in which they are placed anything other than random. Best practice does not necessarily assume that the answer to all of the questions will be "yes". There may be valid reasons why some aspects of patients' expectations of genetics may not be met. Asking the question serves as a stimulus to explain why this is so. Equally, a positive response can provide the opportunity to establish audit trails allowing performance to be monitored against agreed quality standards.

# CHECKLIST

- 1 Has the scope of the service been explained prior to the first appointment?
- 2 Has the difference between “genetic counselling” and “counselling” been made clear?
- 3 Does the service write to patients as well as GP’s **after** the consultation, outlining what has been discussed (even if verbal explanation is given, this may not be understood or remembered. Something on paper remains with them.)
- 4 Is the time scale between all the stages in providing a service (from primary referral through diagnosis to onward management) clear, and have explanations as to why delays may sometimes be necessary been given?
- 5 Is it clear who else will be involved in developing an appropriate action plan for managing the response to the patient’s needs? Do they know? Are they ready and who is going to coordinate it?
- 6 Are referral arrangements to other relevant specialists in place should they be needed?
- 7 Is it possible to provide the time and space to consider the social, psychological and familial issues that may be generated by the diagnosis and referral?
- 8 Is the patient clear about how to get back in touch if he/she/they want to?
- 9 Can the service pick up on previously referred patients as they reach critical phases in the development of their condition (e.g. when children reach puberty, or when progress of the disorder creates changes such as the onset of wheelchair use etc)?
- 10 Are there systems to meet the needs of people whose primary language is not English (including deaf people who may prefer sign language)?

- 11 Is up to date information about relevant support groups to hand and made available to people in ways that allow them to choose when and if to use them?
- 12 Do communications with patients recognize the level of education and understanding of the patient and his/her family?
- 13 Is appropriate written information and communication using other media available to support and expand on the spoken word?
- 14 How can the service assimilate new ideas about managing conditions, especially if these are user initiated and/or come from non-traditional sources (such as the internet)?
- 15 Are there mechanisms to take the service to the patient if necessary and/or appropriate?
- 16 Is the physical environment and the supporting infrastructure conducive to as stress free a consultation as possible? (i.e. have administrative and other support staff been trained in customer care?)
- 17 Does the service provide crèche, respite care or other facilities for dependent others while the consultation is under way and is the availability of these made known to service users?
- 18 Is there a clear understanding about what is and what is not negotiable about the service offered? Is policy publicly available and is it clear how patients can find out about *what* policy is and why it is as it is?
- 19 Is there a quick and easy mechanism for resolving disputes?
- 20 Does the service actively seek systematic feedback from individuals and families in a variety of ways and does it incorporate the results of this feedback in evolving new ways of working?