Learning disability: the interface with genetics Cambridge Genetics Knowledge Park

Patient and Public Involvement Aspect.

The Cambridge Genetics Knowledge Park (CGKP) learning disability project aims to develop an understanding, expertise and capacity of learning disability in Cambridge. This, it is hoped, will ultimately contribute to the improvement of clinical services offered to patients with learning disability.

Given that potential changes to clinical services will affect patients, their families and carers it is imperative that these parties are given the chance to input into the ongoing decision making process. The LD Steering Group considers Patient and Public Involvement (PPI) this important for the sake of transparency, legitimacy and patient rights. Furthermore, we recognise that genetic testing and learning disability are sensitive issues, which must be approached in a manner that evinces a respect for personal beliefs and values. It is vital that we listen to, and take on board such concerns. Hopefully patient and public involvement will ensure that recommendations for change make sense to those that are affected by them. In those cases where it does not, their involvement may assist to pre-empt and respond to alternative viewpoints.

Moving Forward.

This is the second working paper on PPI for consideration by the Steering Group. The first set out some basic principles and models for consideration and discussion. This paper seeks to respond to that discussion in the form of a proposed PPI framework for approval by the Steering Group.

Two principal concerns have been raised about the scope of PPI within the context of the LD project. The first was whether we are equipped to deal with the larger socio-political implications of genetic testing for learning disability. We recognise that there are certain social stigmatisms attached to genetic testing for learning disability and/or genetic testing within a public health context. Whilst there may certainly be a need for a discussion on these issues within the community, we are not capable of providing the type of forum necessary for a meaningful discourse. We must be realistic about what we can achieve through PPI, otherwise those who participate could be left disenfranchised. Equally, should we instigate a debate without being able to see it through to its conclusion we may be left in a situation where only the most vocal or most negative opinions are raised. Either scenario must be seen as counter-productive

The second, related issue, raised during initial discussions, is the challenge of organising and realising an effective PPI process given time and resource constraints. There is no absolute deadline for this project. However, the Steering Group has agreed on producing core deliverables in approximately two years. Certainly, this is a reasonable time within which to undertake some consultation work. However, learning disability presents some hurdles that will need to be overcome. Some patients, particularly those with severe learning disabilities, may have difficulties with communication and conventional methods of communication might need to be explored. Their carers are most often family members, who either work or are dedicated to the care of their child or loved one. To participate in PPI activities necessitates carers take time off work, arrange alternate care and indeed find the energy for extra work.

Finally the budgetary constraints of this project preclude the undertaking of regular or large meetings.

Both of the problems above relate to how broadly we define the scope of the PPI component within the overall project. That is:

- Who should we consult?
- About what should they be consulted; and
- To what degree should they or can they be consulted?

In addressing the first of these questions it is important to reflect upon the remit of the overall project within which PPI activities will operate. Whilst final clarification of the core aims and deliverables is still to be agreed upon, it is clear that the LD project will operate within the individual patient management context and not delve into the question of how genetic tests interface with public health generally. Subsequently the primary focus of PPI activities should be the needs, experiences and concerns of individual patients, their families or carers.

In respect of the latter two questions we must consider the degree to which patients, their families, carers and representatives can be involved in a meaningful and constructive way. An overly broad, or ill-defined process could prove cumbersome, particularly within existing time constraints. There is a limit to how much of their time and energy they a PPI group could reasonably be asked to contribute. It is then imperative that some structure and direction is provided to any group participating in PPI activities and that group's vision and working plan accords with the Steering Group. This will ensure that participant's time is not wasted and that productive and valuable outcomes might be realised.

A Basic Framework

1 Setting out the questions.

Based on the above considerations, it is recommended that a small PPI working group is formed, constituted of between six to twelve members. They should be provided with a clear set of questions that they can answer over the period of a year. Therefore, before the group is established, the Steering Group needs to consider:

- What key project areas would benefit from patient and family input;
- How to frame questions that will contribute to these project areas; and
- How responses might be incorporated into the final deliverables.

Some suggested questions are set out below.

2 Gathering Members.

Once a clear agenda is set, we should use existing networks, including patient groups and the extensive contact base of Steering Group members to call for PPI participation. It would be helpful to have a strong representation from interest group leaders as they act as information conduits to the greater LD community.

3. Addressing the Questions.
The PPI group would address key questions over a series of meetings. It might also identify any further questions that might need to be addressed in a final report, either by the PPI group or the Steering Group.

4. Online Collaboration.

To minimise the number of meetings and the need to travel to a central location a secure online forum has been established which would allow group members to: upload documents and resources; leave comments about materials; and undertake discussion about PPI progress. The online forum is secure, requires a username and password to access and cannot be reached from any external website link. A similar forum may be established for the Steering Group. By using this forum the PPI group may be able to be include parties who are interested in participating but are unable to attend meetings.

5. Deliverables.

At the end of the allocated period the PPI group would produce a short report with the key responses and recommendations. It might also provide feedback on Steering Group work, including guidelines, report and website.

Some questions.

Some of the questions which might be worth presenting to the PPI group are se out below. It would be beneficial to decide on between six and ten questions that provide enough guidance but are sufficiently flexible to allow internal dialogue.

What information on genetic testing for learning disability should be made available online?

What competencies would you expect of professionals in this area?

- Basic guidelines and information about tests available on website (see 2 above)
- Access to more general useful information about conditions, sources of support, ELSI issues etc on www

What benefits can be gained for patients and their families by genetics diagnosis? We need to be able to justify this now and for future services.

When might an adult with LD or their family benefit from further genetics services? - evidence (see link to X)
What are the issues around identifying these points of need?
What ethical, legal and social issues arise and how should these be dealt with in a practical sense.

What are the prevailing attitudes of professionals towards genetic testing?

The patient and family experience of a named diagnosis in garnering special support

Bring a small focus group together to review the work that is being undertaken by the Steering Group.

What educational support is available to help all these individuals gain these genetics competencies?

In particular- what competencies do community paediatricians and specialists in adult learning disability need in this area, and how can they be kept up to date.

In terms of guidelines,

what the information flow will be for test results, how and by whom these should be communicated to parents and patients?

The scope and direction of the project is still to be decided upon by the Steering Group. Until such time as clear

Proposals for some main areas of work

Through involving the public we could:

- learn more about patients', people with learning disabilities', their family's and carer's experience of current clinical practice, including genetic assessment and testing;
- identify target issues and needs of people with learning disabilities with respect to genetic assessment and testing, so that future services can be better adapted to respond to patients' needs;
- better understand the knowledge, perception and reaction to genetic testing for learning difficulty among people with learning disabilities, their families and their carers;
- identify communities who might benefit from genetic assessment and testing but who are currently not receiving such services, the reasons for this and how, or if, future services can be provided to these communities;
- allow alternative proposals to be explored and/or developed;
- anticipate and respond to potential public criticism or backlash to findings.

What information would you expect

Other Reasons

There are many other benefits to including the public in our work, some of which may only become evident during the course of this project. Some of the more likely outcomes include:

- a source of case studies/personal stories. Such stories contextualise recommendations give them a 'human face' and highlight the importance of proposed changes to those affected by the disability. Moreover, these are not case studies obtained through a unidirectional interview process, but the stories of those who participated in the process of creating the report and its recommendations for change;
- a consultative panel (if this model is adopted) providing a valuable resource with which to gauge the readability and accessibility of our public documents;
- transparency of the decision making process;

- the experience and knowledge of patients, the public and local communities can be used to benefit others and other studies; and
- trust is built between communities; the NHS and the CGKP.

1. Public Involvement: An Ongoing Process

Public involvement cannot be a one off process. It needs to be analytic, responsive and iterative, feeding into the study, influencing work in progress as well as being influenced by that work. Adequate time and resources need to be dedicated to responding to and/or incorporating public views into our work. Given that a variety of interested parties may wish to be involved, the content of information might need to be tailored (and re-tailored) to suit individual needs.

Part of the involvement process may be to discuss with stakeholders the best way to ensure and improve upon further involvement. For example, it may become clear that:

- more effort needs to be made to involve the harder-to-reach groups;
- more information needs to be given; or
- a formal consultation process lasting for a set period of time is/is not necessary.

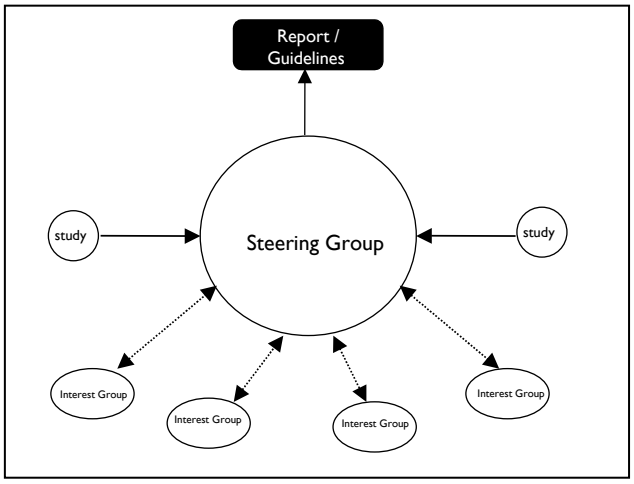
Considerations For A More Effective Public Involvement Aspect

- Real patient and public involvement is not about ticking boxes, it is about developing constructive relationships, building strong partnerships and communicating effectively.
- The mechanisms for involvement should constantly be evaluated for their effectiveness.
- It is important for the CGKP to demonstrate how it has listened and responded to feedback and show how patients and the public have influenced service improvement. This will encourage further participation both in this project and others. It will hopefully make participants feel their contributions are considered and valued.
- We may need access to training and for interested parties to participate in an informed and constructive manner.
- The public should be represented by a wide range of individuals and groups and not by particular 'patient groups'. (Bristol Report)

2. Issues/Challenges

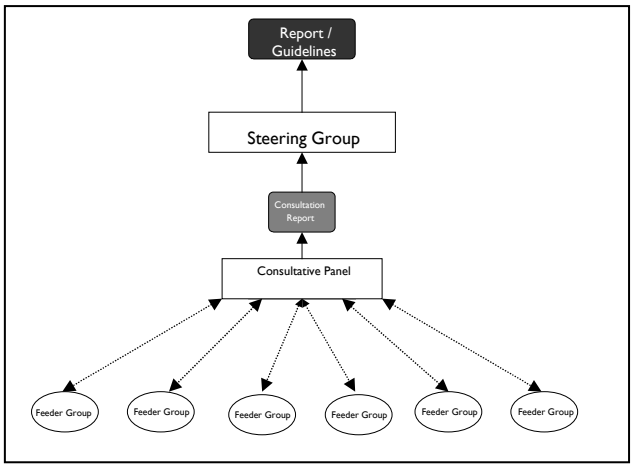
- ***Knowledge Barriers***: it is important to identify and respond to the varying levels of understanding and education among participants. This may necessitate undertaking a multi-message and deliberative approach.
- ***Social Barriers***: existing perceptions of the importance of genetic testing to learning disability – encouraging people to participate if they believe there to be no issue to start with.
- ***Communication Barrier***s: "Many people with severe learning disabilities have difficulties with communication. Finding ways in which people can communicate, and ways other people can communicate with them, can make a big difference to people's quality of life." (Foundation for People With Learning Disabilities UK). How do we enable people with learning disability to make a contribution?

3. Consultative Models



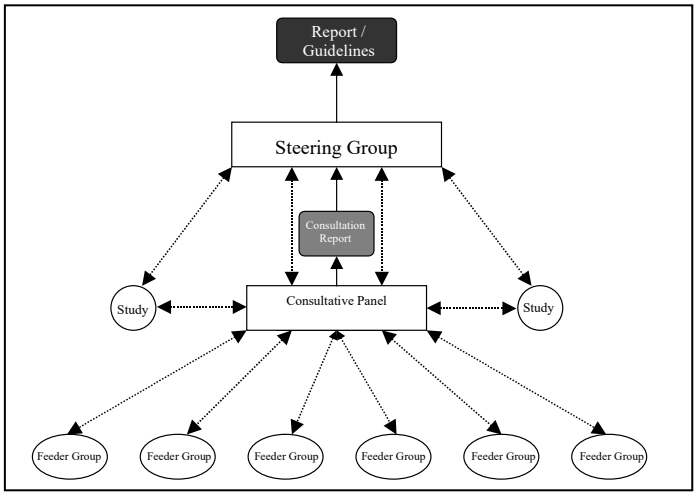
Centralised Model

Benefits	Negatives
Strong direction from Steering Group Able to focus on specific issues Can address questions as they arise	Limited networking ability Can prove costly if several studies are needed Less interactive / community oriented Question oriented: may not identify all community concerns



Consultative/Distributive Model

Benefits	Negatives
Broad participation through feeder groups Community oriented and driven Little chance for allegations of interference/bias Relatively Inexpensive Response oriented: may identify concerns not explored by Steering Group	Less direction from Steering Group Harder to focus on specific issues May not result in as strong a relationship between Steering Group/ community



Combined/Integrative Model

Benefits	Negatives
Both Question and Response oriented Broad participation through feeder groups Able to focus on specific issues Can be directed/focused where necessary Interchange of ideas at all levels of study	Must be properly managed Can become expensive Harder to integrate information within time constraints

4. Methodology

Stage 1.

- Review existing social science research work, particularly that of the Centre for Family Research.
- Pre Consultation of Interested Parties
- Visit Schools/Special Schools/Respite Care Homes
- Outline objectives
- Establish timeframe
- Discuss and Address critical Issues with project group
- Produce initial briefing documents

- Initial news story in local paper to create interest.
- Advertisement in local paper or on local radio
- Establish feeder network
- PGHU Website
    - web page dedicated to project; o
- online database
    - email list.
    - bulletin Board.
    - FAQ

- Monitoring and Evaluation.

Stage 2.

- Establish Consultative Panel
- Determine Agenda.
- Formulate Strategy
- Patient surveys / diaries.
- Focus Groups
- Feedback and Update Documents
- Post Consultation Identification of Interested Parties.
- Monitoring and Evaluation.

Stage 3

- Press Releases / Sample stories
- Newsletter
- Material Distribution – posters/pamphlets
- Monitoring and Evaluation.

Stage 4

- Creation of Public Report to contribute to final CGKP report.

5. Pre-Consultation Identification of Interested Parties.

- Patients
- People with learning disabilities(children/mature)
- Families/Carers
- Learning disability citizen advocates (FPWLD)
- CGKP staff
- Centre for Family Research
- Social workers
- Social scientists
- Ethicists

- Special educational needs coordinators;
- Teachers
- Classroom assistants
- School counsellors
- Education policy officers
- Educational psychologists

- Genetic counsellors
- Clinicians

- Special interest groups
- Addenbrookes PPIF/Patient Panel Members
- Lay people.