Introducing PROMs in NHS Clinical Genetics Services

MARION MCALLISTER
18 November 2014
Introduction

- Background
- Qualitative research
- Systematic review & Delphi survey
- PROM development
- Quality improvement & Future plans
A clinical genetics service is a specialist service provided by the NHS, which offers

1. diagnosis of genetic conditions
2. information about genetic conditions including information about inheritance and risks to unaffected/unborn family members
3. genetic testing
4. supportive counselling to help the family make decisions and cope better with the genetic condition in their family

The service is offered to all members of a family in which a genetic condition may be present, not just those who have the condition.
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..... most genetic condition can be neither treated nor cured.
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..... but may have serious implications for other relatives and future descendants.
Measuring quality in NHS clinical genetics practice

Quality measures:
- Number of genetic tests done
- Waiting times
- Numbers of patients attending
Nowgen research programme

- Katherine Payne
- Marion McAllister
- Rhona MacLeod
- Stuart Nicholls
- Dian Donnai
- Linda Davies
Systematic review of validated measures

What validated outcome measures are available to evaluate clinical genetics services?

Systematic review of validated measures

61 articles.

Patient reported (subjective) outcome domains:
67 validated Patient Reported Outcome Measures identified
1. Psychological distress
   (anxiety, depression, worry)
2. Coping
3. Decision-making
4. Family environment
5. Health status
6. Knowledge
7. Mood
8. Perception of risk
9. Perceived personal control
10. Quality of life
11. Satisfaction and expectations
12. Self-esteem
13. Spiritual well-being

Objective outcomes:
   a. Accuracy of diagnosis
   b. Accuracy of tests
   c. Rate of terminated pregnancies

Systematic review of validated measures

Conclusions:
• Very limited assessment of important psychometric properties
• Some aspects of the potential patient benefits not captured by existing measures
• More research is needed
• Patients’ views should be used to target measure(s) to the aspects that benefits them directly

Outcome domains: Delphi survey

Aim: to identify the degree of consensus about the relevance of existing outcome domains

• 115 genetics clinicians and 72 patients

Payne et al. (2007) *Health Policy* 84: 112-122
Outcome domains: Delphi survey

Aim: to identify the degree of consensus about the relevance of existing outcome domains

- 115 genetics clinicians and 72 patients
- At least 75% of the panel agreed that the following outcome domains were useful:
  - Knowledge of the genetic condition
  - Decision-making
  - Perceived personal control
  - Risk perception
  - Satisfaction
  - Meeting of expectations
  - Coping
  - Accuracy of diagnosis
  - Quality of life
Nowgen qualitative research

What do patients and clinicians value about clinical genetics services?

Interviews and focus groups:
• 30 patients
• 34 representatives from patient support groups
• 24 genetics clinicians
• 4 service commissioners (payers)
Data analysed using grounded theory

http://www.manchesterbrc.org/OurFacilities/Nowgen.php
http://www.nowgen.org.uk/facilities/TheNowgenCentre.php
Patient-reported outcomes from clinical genetics services

Empowerment

5 Dimensions of empowerment:

Patient-reported outcomes from clinical genetics services

5 Dimensions of empowerment:

1. Decisional control

Patient-reported outcomes from clinical genetics services

5 Dimensions of empowerment:

1. Decisional control
2. Cognitive control

Empowerment

Patient-reported outcomes from clinical genetics services

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2. Cognitive control
3. Behavioral control

Empowerment

Patient-reported outcomes from clinical genetics services

5 Dimensions of empowerment:

1. Decisional control
2. Cognitive control} Perceived Personal Control
3. Behavioral control
4. Hope

Patient-reported outcomes from clinical genetics services

Empowerment

5 Dimensions of empowerment:

1. Decisional control
2. Cognitive control
3. Behavioral control
4. Hope
5. Emotional regulation

Empowerment

“... Information is power, (you’re) powerless if you don't have information and that's one of the problems that we've come across. Families feel isolated, they have anxiety because they have no information, therefore they have no power.”

(patient group representative, children have a mitochondrially inherited metabolic condition)
“... because (husband)'s got the condition and I haven't, the chances of our children having it are 50/50, and [...] because the children both have it they too have now a 50/50 chance of passing it on to their children, which we didn't know until we went for this genetic counselling. So it didn't make any difference to our decision making but it may make a difference to the children's decision making, and of course we can give that information (to them) having been given it ourselves ...”

(patient group representative, both children have Hereditary multiple exostoses)
# The Genetic Counselling Outcome Scale (GCOS-24)

Using the scale below, circle a number next to each statement to indicate how much you agree with the statement. Please answer all the questions. For questions that are not applicable to you, please choose option 4 (neither agree nor disagree).

1 = strongly disagree  
2 = disagree  
3 = slightly disagree  
4 = neither disagree nor agree  
5 = slightly agree  
6 = agree  
7 = strongly agree

|   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| 1 | I am clear in my own mind why I am attending the clinical genetics service. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | I can explain what the condition means to people in my family who may need to know. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | I understand the impact of the condition on my child(ren)/any child I may have. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | When I think about the condition in my family, I get upset. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5 | I don’t know where to go to get the medical help I / my family need(s). | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6 | I can see that good things have come from having this condition in my family. |     |     |     |     |     |     |     |     |
The Genetic Counselling Outcome Scale (GCOS-24)

Using the scale below, circle a number next to each statement to indicate how much you agree with the statement. Please answer all the questions. For questions that are not applicable to you, please choose option 4 (neither agree nor disagree).

<table>
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GCOS-24

- Empowerment is a valued outcome from using clinical genetics services (genetic counselling and/or genetic testing)

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- GCOS-24 can measure empowerment because we have generated evidence that it is
  - Reliable
    - Internal consistency $\alpha = 0.87 \ (n = 549)$
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• Responsive to change over time
  • $t = 12.56, p < 0.001 \ (n = 241)$
  • Cohen’s $d = 0.7$ (medium-to-large)

Evaluation of clinical practice

1. **Glasgow 2011:**
   - GCOS-24 sent with appointment letter
   - GCOS-24 sent 4-6 months after appointment

2. **London 2012:**
   - GCOS-24 sent with appointment letter
   - GCOS-24 sent 2-4 weeks after appointment
     - North West Thames
     - Guy’s
     - St George’s
     - Great Ormond Street

3. **Cardiff 2012:**
   - GCOS-24 sent with appointment letter
   - 2-4 weeks after appointment:
     - GCOS-24; H Skirton Audit Tool, Zellerino
# GCOS-24 Service Evaluation

<table>
<thead>
<tr>
<th>Centre</th>
<th>Centre 1</th>
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<td>Mean Change score</td>
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Conclusions

• Clinical genetics services can deliver measurable patient benefits, as measured by GCOS-24
  • *BUT* there is uncertainty about representativeness

• Patient benefits captured by GCOS-24 correlate significantly with patient satisfaction
“The view from the London Specialised Commissioning Group ... is that in the past it has been difficult to identify and quantify outcome measures because genetics is either part of an overall treatment pathway or it advises patients on how to manage and live with their genetic condition. As such, outcome measures have not been sophisticated enough to measure their outputs. The ability to identify a range of tailored specific outcomes is welcomed and will enable commissioners to procure high quality and cost effective services which benefit patients so they can make more informed choices about their lifestyle.”

Sandra Tribe, Senior Commissioning Manager, London Specialised Commissioning Group
Quality improvement

Figure 2: The Seven Steps to Measurement

The seven steps to take are:

1. Decide aim
2. Choose measures
3. Define measures
4. Collect your baseline data
5. Analyse and present your data
6. Meet to decide what it is telling you
7. Repeat steps 4 to 6 each month or more frequently

Quality improvement

- GCOS-24 and EQ-5D
- To develop a team-based approach (“intervention”) to using patient feedback for quality improvement
  - Relational co-ordination theory
  - Behaviour change wheel
Quality improvement

• Cardiff Business School seedcorn funding £2500
  • Aoife McDermott, Andrea Edwards, Marion McAllister
• Pilot study:
  • Team approach to collect, report & use patient feedback (PROMs, complaints) for CQI in NHS clinical genetics services
  • Identify barriers & enablers to starting, spreading & sustaining the team-based innovation
  • Collect preliminary data to support a funding in 2015 for a larger study to develop and evaluate a complex healthcare management intervention
In a structured way...

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• Approach:
  • Collect, analyse PROM data (MSc student)
  • Qualitative interviews with GC team members
  • Present emerging themes to GC team for discussion
    • Resources, barriers, enablers, usefulness, spreadability, frequency of team meetings, management of team workshops, recording of decisions made, actions arising, ways to evaluate the model
Future plans

- Use findings to develop (specify) a complex healthcare management intervention to support using patient feedback data for CQI
  - Aoife McDermott, Andrea Edwards, Marion McAllister
- Apply for funding in 2015 for a larger study to develop and evaluate the healthcare management intervention