Story and Testing of the Scottish Spiritual Care Patient Related Outcome Measure Scottish (PROM)

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And
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Sharing Innovative Practice

Strategic Development and Leadership

Research – PROM
(national research programme)
Aim

Describe context out of which PROM arose

Why PROM needed and why strategic planning required

Process of education regarding research in chaplaincy in Scotland

How PROM developed involving chaplaincy practitioners

Findings
NHSScotland

Pop. 5,347,600

Chaplains – 68 w/t
65 p/t
History of Scottish Chaplaincy

Traditionally administered by churches yet often generic (Pt-time > W/T)


DIRECT EMPLOYMENT by Health Service (mid 2000s) – generic and W/T > Pt-time


National educational officer post replaced by strategic leadership post (2009)

Formational of National Strategic Leadership Group – 2009
Recommendation 3

NHS Boards are asked to:

promote research which broadens and enlightens the evidence base for the efficacy of spiritual and religious care in health (2008)
Scottish Context 2009 - principle challenges in health and social care

- Financial austerity
- Rapid Demographic Changes
- Multiple long-term chronic conditions – >75% of burden of disease in most industrialized countries (WHO 2010)

Loss of function
Loss of role
Loss of identity
Loss of meaning
Loss of purpose

- Health Inequalities/Poverty
- Loneliness and Isolation
- Staff/provider/carer stress
Can longer provide healthcare way we have provided it in modern era in ............

........SCOTLAND

- No. of people >75 from 2013-2023 will increase by 25%
- No. of people >75 by 2033 will have increased by 60%
- In 2013 71,000 people diagnosed with dementia,
  By 2033, 127,000
- By 2033 changes in demography alone could increase expenditure on health and social care by over 70% (Scottish Government 2013)
What spiritual needs are out there in Dumfries and Kirkcudbright?
Paradigm shifts informing health and social care provision

Direction of travel from:

1.1 treating ill-health to **promoting wellbeing**

1.2 professional prescribing to empowering patient self-management

1.3 working with what is broken and needs fixed (deficits) to naming and fostering assets in health and social care

1.4 focusing on Acute Care to enhancing and developing Primary and Community Care

1.5 focusing on ‘the individual’ to helping groups and communities become resilient and make sense of things

1.6 institutionally based to community based activity
Scottish Chaplaincy 2009

Low profile and not understood/relevant

Reactive not proactive

In the main peripheral, want to do ‘own thing’, resistant to accountability yet paid by tax payer

Little coherence, collaboration

Little or no evidence base – qualitative

Primarily SITUATED IN ACUTE/DEFCITS BASED CULTURE – focus on ill-health not promoting well-being
Strategic Leadership

Dance floor to Balcony

Vision and innovation

Coherence, Collaboration and Communication

Political/policy engagement and increased profile

Proactive not just reactive
Theology of strategic leadership – innovation, collaboration and envisioning

**Meaningful risk – incarnational** – taking steps into the unknown utilising the abilities and skills chaplains possess
- self-awareness
- relational
- theol. reflective practice

**Wisdom (SOPHIA)** - the right risk at right time with right people

**Work to manifesto/strategy/plan/intention** – Jesus use of Isaiah in the synagogue in Nazereth (Luke 4:16f)

Jesus sent the 70 out and on return reflective practice – Luke 10:20 being loved by God doesn’t depend on success
Consensual Strategic Priorities

- Research
- Formation/Education and Training – reflective practice and supervision
- Communication
- Innovation - National collaborative and collective programmes of work
Policy and funding—waiting for the right wave—to maximize strategic profile and impact
3 Quality Ambitions:

- Person-centred
- Safe
- Clinically Effective
Scottish Government’s 2020 Vision for Health and Social Care

Our vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting.

We will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self management. When hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm. Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions. There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate, with minimal risk of re-admission.
Route Map for 2020 Vision

3 of 12 Priority Areas to inform direction of Travel

- Person-centred Care
- Innovation
- Primary (non-acute) Care
Person Centred Care – helping health boards to deliver and evidence

<table>
<thead>
<tr>
<th>Workstream of Government’s person-centred policy</th>
<th>Scottish Chaplaincy’s National Programme of Work</th>
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<tbody>
<tr>
<td>1. Co-production (supporting Self management)</td>
<td>1. Community Chaplaincy Listening (CCL)</td>
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<td>2. Care Experience</td>
<td>2. Scottish PROM</td>
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<td>3. Staff Experience</td>
<td>3. Values Based Reflective Practice (VBRP)</td>
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<td>4. Leadership</td>
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Community Chaplaincy Listening

>60 sites across Scotland – GP surgeries, voluntary sector, Staff support

- Referral by GP, other health and social care pros, self
- People dealing with loss and transition who want to enhance their wellbeing.
- 1-4 x50 minute sessions
- Assets based
CCL - Spiritual Care/Listening

Focus - meaning and purpose
identity as a unique human being

- Need to love and be loved
- To be creative
- To find hope
- To give and receive
- To connect with beauty and otherness/transcendent

Adapted from Naryanasamy (1991)
Spiritual Need met by....

Assets/resources:

- Within us
- Between us
- Around us
- Beyond Us

And the tasks and roles we find fulfilling and meaningful
Eliciting Assets

What gets you up in the morning?
What is important to you?
What matters to you?
What raises your spirits?
How have you coped in the past in difficult times in your life?
What makes you feel alive?
Funding for Research and Innovation

From Scottish Government (£500,000 – over 4 years)

- Relationships
- Understanding policy priorities/levers for funding and who responsible for delivering
- Start small and plan bigger – build credibility
- Strategy – pilot foundation/springboard for larger projects
- Collaborative partners
Evidence Based Practice

Funding for research for innovative practice that helps shift way we practice health and social care.
National Research Strategy – growing and nurturing research and evidence based practice

- Research literate
- Research supporters
- Researchers

RESEARCH – ON THE SAME CONTINUUM AS REFLECTION ON PRACTICE
National Research Strategy – growing research and evidence based practice

Education – action research - praxis – Scottish Journal of Healthcare Chaplaincy 13(1) 2010
http://www.sach.org.uk/journal/journal1301.htm

Research Champions (in each area of Scotland) → PROM Champions

Communication – regular newsletter, events/conferences, strategic leadership group

Support/mentoring

Fostering specialist research – funding doctorates
Strategic Impact of attempting PROM Research

Political – at national and local levels

Raised Profile – professional, relevant and innovative

Credibility of chaplaincy – quantitative and qualitative

With civil servants, managers, academics and clinicians
Strategic Development of the Scottish PROM

Pilot – LOTHIAN PROM

National Scottish PROM

Multi-site Studies
PROM: Summary background

- Chaplains are employed by health organisations around the world to support patients with their spiritual needs.
- There is currently no generalizable measure of the impact of these interventions and so the clinical and strategic worth of chaplaincy is difficult to articulate.
- This part of the presentation introduces the Scottish PROM, an original five-item patient reported outcome measure constructed, refined and tested over a five-year period specifically to address this gap.
What is a PROM?

A patient reported outcome measure (PROM) is a self-reported questionnaire that assesses quality of life or perceived health status.
Why do we need a PROM?

- There is currently no generalizable measure of the impact of chaplain interventions and so the clinical and strategic worth of chaplaincy is difficult to articulate.
- Ewan has just provided the strategic, political and clinical context as to why this is important.
- Chaplains are currently reliant on case studies or psychometrics designed for a different purpose.
The process of developing a PROM

<table>
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http://asm.sagepub.com/content/18/3/263.short (June 9, 2012).
Process of developing the Scottish PROM

- **Conceptual**
  - What do chaplains do?
  - What benefit do patients get?

- **Systematic check**
  - What scales are already available?
  - What are the gaps?

- **PROM construction and testing**
  - Create item pool
  - Test PROM
Conceptual model:
The patient benefit of being with chaplains

Positive outlook
Peace
Control
Distress relief
Honesty

The original PROM items

- In the last two weeks I have felt:
  - In control of my life
  - Anxious
  - A sense of peace
  - I had a positive outlook on life
  - I could be honest with myself

- Responses: strongly disagree to strongly agree
Testing timeline

2011: Focus groups, chaplain conferences
Original Lothian PROM

2012:
37 participants validated
Lothian PROM: 111 page report

2013:
3 publications
4 conferences
National study planned

2014:
Scottish PROM refined. Ethics permissions for CCL study
Paper on ethics

2015-16:
Data gathered from national study validating Scottish PROM
## The Scottish PROM

In the last two weeks I have felt:

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>Rarely</th>
<th>Some of the time</th>
<th>Often</th>
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<tr>
<td>I could be honest with myself about how I was really feeling</td>
<td>○</td>
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<td>Anxious</td>
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<td>A sense of peace</td>
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The process of developing a PROM

- Create conceptual model
- Develop item (question) pool
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- Refine item pool
- Test PROM in relevant sample
- Refine items
- Test in larger sample(s)
The next steps: test PROM in relevant sample

- The PROM has to have internal consistency: be RELIABLE
- The PROM has to be VALID: it needs to show convergent validity with a comparable, already validated measure (WEMWBS)
- If it is valid and reliable it is a robust measure of chaplaincy interventions in this study
A reliable PROM

- Honesty
- Control
- Perspective
- Peace
- (less) Anxiety
An unreliable PROM

- (less) Anxiety
- Honesty
- Control
- Perspective
- Peace
A reliable PROM is internally consistent:
Convergent validity = correlation with other relevant scale
No correlation

CCL
PROM

WEMWBS
Complete correlation
The goldilocks zone!

CCL

PROM

WEMWBS
In mathematical terms:

\[ y = x \]

\[ R^2 = 1 \]

Too good

\[ y = 3 \]

\[ R^2 = 0 \]

No good

\[ y = 0.74x + 0.66 \]

\[ R^2 = 0.67372 \]

Perfect!
Method

- **Design:** Survey conducted 2014-2016.
- **Chaplain intervention:** Community chaplaincy listening service. Patients referred by GPs were seen by chaplains in primary care to help address whatever spiritual needs they had.
- **Project participants:** People discharged from community chaplaincy listening service.
- **Process:** Discharged participants sent survey by post
- **Survey:** Demographics, experience of chaplain, Scottish PROM, WEMWBS, free text box.
Results

- 103 of 252 surveys were returned (41%).
- Mean (SD) age was 54 (14.5) years, ranging from 19 to 92 years.
- 70 participants were female, 33 male.
- 32 people were religious, 16 spiritual, five both and 48 neither.
- Mean (SD) number of consultations was 2.5 (1.7).
Mean responses to individual PROM items. In the last 2 weeks I have felt:

- I could be honest with myself about how I was really feeling: 3
- Anxious (reversed): 2
- I had a better outlook on my situation: 3
- In control of my life: 3
- A sense of peace: 2
Results

- Maximum possible Scottish PROM score was 20. Mean response was 13 (3.3), with range 3 to 19.
A reliable and unidimensional PROM?
Yes!!

- Cronbach’s alpha for the full scale was .81 indicating **very good reliability**.
- Principal component analysis revealed a single factor solution accounting for 57% variance, indicating **unidimensionality**.

### Component Matrix

<table>
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<td>I could be honest with myself about how I was really feeling</td>
<td>0.616</td>
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<tr>
<td>I had a positive outlook on my situation</td>
<td>0.823</td>
</tr>
<tr>
<td>In control of my life</td>
<td>0.834</td>
</tr>
<tr>
<td>A sense of peace</td>
<td>0.896</td>
</tr>
<tr>
<td>Anxious</td>
<td>-0.577</td>
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A Valid PROM?
Yes!!

- There was a **high positive correlation** between the scores on the Scottish PROM and the WEMWBS, $r(101) = .803$, $p < .0005$. 
Interpretation

- The Scottish PROM is **reliable, unidimensional and valid** in this population.

- Because it is grounded in a strong conceptual underpinning it is a **robust measure of the outcomes of chaplaincy interventions**.

- Further psychometric examination is needed and planned, but these results are extremely promising:

- **The Scottish PROM offers a currently missing opportunity to international chaplains and their managers to add purpose built psychometrics to their evidence base when discussing their unique contribution to care.**
Next steps

- Australian study (N=400) reporting soon
- Two English studies using Scottish PROM
- My colleague Iain Telfer in Florida at conference and board meeting APC
- NES funding ‘before and after’ study using Scottish PROM to measure impact of chaplaincy intervention (what difference do chaplains make?).
- Plan to test PROM in European sample
The world of chaplaincy is changing.

How ready are chaplains for engaging with the evidence base for their activities?

Association of Professional Chaplains (APC – USA) sent questionnaire to chaplains around world to explore their attitudes to research.

Over 2000 chaplains responded in April 2016:
Respondents

- USA, 1362
- UK, 162
- Canada, 156
- Netherlands, 148
- Australia and NZ, 140
- Other, 30
- Missing, 94
How research literate?
Implications of survey

- The chaplain population is heterogeneous
- Education is associated with research literacy
- Attitudes to research are overwhelmingly positive
- Something as simple as the PROM may help turn this enthusiasm into activity?
Impact Strategically and on Practice in Scotland

- ‘Gold star’ valid quantitative and qualitative evidence
- Confidence – ‘pastoral integrity’ (Capps)
- Cultural change – research integral to chaplaincy
- Raised chaplaincy profile – nationally and locally
- Chaplaincy innovatively helping to change way health and social delivered - proactive
- Changed others’ perception – chaplaincy as a profession
- Created opportunities for chaplaincy in Scotland
Learning

- Importance of communication and collaboration
- Resistance to change – human nature and Church vs healthcare culture – esp rapidity of change
- Paradox – chaplaincy community want to be recognised and valued yet fear of ‘head above parapet’ and raised expectations
- **Recruitment and formation – individual and professional confidence**
- Ongoing Education and training/mentoring – **leadership and research**
- Go where the energy (and policy) is!
References


Snowden, A., and I. Telfer. 2015. “CCL PROM: To Validity and Beyond.” In *Spiritual Wellbeing at the Heart of Person-Centred Care: Co-Creating Community Through Research and Innovation*, Glasgow. 