Working together in practice

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Context

- Patients Association – independent charity
- National Helpline- information and support
- External challenge and lobbying
- Projects to influence change involving patients
- Devon and Cornwall (240 practices) and Waltham Forest (44 practices)- PPG projects
- Keen to see patient groups have influence and make a positive contribution to the NHS
- Provide a community network for engagement
- Act as critical friend- relationship of equals, mutual respect, openness and trust
We are a national independent non-disease specific health and social care campaigning charity that also works locally to improve experience of care. Working with NHS Trusts and other organisations across the country, we are able to speak up for change and help influence service improvement for the benefit of patients, carers, members of the public and staff. Our independence is very important in this.
Key aspects of our work

**Patient Safety**
- Ensuring learning from serious incidents and complaints
- Listening to patients and families
- APPG in Patient Safety

**Patient Involvement**
- Shared decision making at all levels
- Individual to strategic
- Move to co-production
- Relationship of equals

**Improving complaints processes**
- Good practice standards
- Complainants survey & benchmarking
- Peer review

**Patient Experience**
- Independent
- Gathering patient feedback independently

**Information**
- Patients’ rights and responsibilities
- NHS Constitution
- Patients’ rights and responsibilities
Examples of our projects
with links to Francis report recommendations

- Improving Dementia Care  – 173 129.
- Mystery shopper 173 129. 109.
- Patient/Carer Perspective of Intentional Rounding 238. 241
- Meeting Patients Needs at Mealtimes 241 129.
- Observation audit in A&E 241
- Shared decision making in medical training 185. 135. 3.
- Health information in primary care & libraries 4. 3.
- Community Reporting –films patient stories 160 135. 129.
- CARE campaign and audit 160
- Patient feedback on facilities 238. 241 129.
- Patient information about medication 4.
- Customer Care Training 109. 4.
- Staff leadership 160
- Observations – to understand quality of interaction between staff and patients 185. 241 129. 109.
- Identifying Carers’ Views and staff training 129. 109.
- Patient feedback on Gynaecology Services 129. 109.
- Council of governors training 129. 4.
- Involving patients and carers in commissioning 135. 109.
- Achieving compassion in practice – improving response times to patient needs using the 6Cs 238. 185. 160
- Patient leaders and involving local community in owning their hospital (Keogh review site) 129. 109.
- Discharge to care homes 239 109.
- National Audit of intermediate care – film 241
- Unheard voices – care homes outreach 239 129.
- Discharge to escalation wards 129.
- Ambassadors on Keogh and CQC review 58
Patient must be at the centre

- NHS is under considerable strain
- Increasing demands and reorganisations
- Duty of candour and better regulation
- Must be implemented properly
- Frustrated callers call our helpline in despair
- Gap between commitments in the NHS Constitution and reality of being a patient
- Never been more of a need to gather patient feedback and make use of it
Benefits of PPGs

- Valuable resource to support the practice
- Improves two-way communication
- Breaks down barriers, builds understanding of patient needs and staff limitations
- Assist with Friends and Family Test
- CQC Registration/inspection
- Health Promotion, education/information- support groups/information fairs/talks/ appropriate use of NHS
- Critical friend – complaints monitoring
- Education for other NHS Staff re patient involvement – student pilots
- And is a GP Contract requirement.................
PPG Project Devon and Cornwall

- 8 local workshops
- Discussions with GP practice staff and patients
- Greater understanding of role and purpose
- Sharing experiences
- Highlighted challenges and issues
- New ideas for widening recruitment
- Information and support pack
- Report with recommendations
- Student pilot – links with Plymouth University
Current issues with Patient Groups

- Lack of consistency - some doing well/others struggling or non existent
- Clarity and direction needed
- What are they for? What could they achieve?
- Culture and views of staff re patient involvement
- Need to recruit from wide variety of patients
- Not just a committee meeting - reach out
- Better use of virtual PPGs
- Not one model – emerging ideas /huge potential


**Recommendations from project report – PPGs should...**

- be clear of their role and relationship with the practice
- have an active and influential role in CQC inspections.
- have support to develop as critical friends
- provide external scrutiny, advice and information from/to patients and staff
- be seen as a positive resource to practices
Work with Plymouth University

- Student nurse pilot project with PPGs
- Expanding to other students/patient groups
- Article in Nursing Times this month
- “Working together” guide and animation Learning from research and evidence base
- Links with Leyton College Sixth Form
- Other universities taking up the idea
- Waltham Forest CCG
- Influencing future practice
What makes a good patient group?

- Good terms of reference (TOR)
- Strong chair
- Structured meetings
- Trusting relationship - staff and patients
- Understanding of purpose and action plan
- Appropriate involvement of practice staff
- Culture of working together as equals
Barriers

- Difficulty in recruiting new members
- Suitable times and venues for meetings
- Lack of commitment from practice staff
- Need to regularly refresh membership
- Only having a virtual group
- Lack of purpose for the PPG
- Inability to think differently
- Sticking to one model of a committee meeting = PPG
- Lack of reaching out to local community
Workshops today

- How do you gather and use the feedback from a wide variety of patients?
- What existing data/information do you use?
- How do you get it? Is it useful?
- Are there other ways to collect people’s views? Be more creative - think differently
- How do we reach wider communities, different types of people?
- Panel discussion - different organisations and what do they do?
Patient Feedback: what we are learning from patient and public involvement (PPI) research
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<tr>
<th>Statement</th>
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<tr>
<td>Enhanced quality, relevancy and appropriateness</td>
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<td>Empowerment</td>
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<td>Personal/professional development</td>
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<td>Strengthened relationships</td>
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<td>Enhanced awareness/understanding</td>
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<td>Enhanced social, cultural and religious inclusivity</td>
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<td>Access and opportunities</td>
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<td>Beneficial attitude, assumption and behaviour change</td>
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<td>Enhanced community and individual wellbeing</td>
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What do we know already?

- Initiatives are many but unconnected and reported in different places
- There is little agreement over best practice approaches, or coherent feedback strategy
- Patients and the public remain largely under-represented in the development of strategies and tools

The agenda going forward

- Working together to articulate a clear rationale for, and providing robust evidence of:
  - the *systematic* and *progressive* role data from patients, publics and lay representatives have
  - in the mentoring, assessment and support of health care professionals and services
  - for patient centred service improvement, and reflexive professional practice and life-long learning

But who do we want feedback from?
Lay Representatives

- Non-health professional or non-specialists
- Emphasis on possessing & applying relevant skills & attributes (changing)
- Sometimes renumerated and usually provided with in-house training
- In PPGs a conduit to patients
Public Groups

- Collective ‘patient voice’
- Recruited through branded organisations
- Typically acting in the interests of ‘consumers’ of healthcare services
Patients

- unique role in education based on experience
- an immediate, personal engagement with doctors
- require tools and support but not specific skills
All parties keen to provide/procure feedback

But many view medical practice as bounded by systems and rules, which may limit feedback

Patients feel able to assess communication skills
Patient data: what’s it for?

- patient feedback for the purposes of feedback for professionals?
- patient feedback to feed back on teams and services?
- Patient involvement to achieve either or both?
- official complaints via fitness to practise system?
Patient complaint

- Random bad luck?
- Inconvenience?
- Misinformed?
- Insult?
- Personal attack?
- Ingratitude?
- Annoyance?

...OR

Assessment and improvement opportunity
Patients: concerns over biased selection of patients for feedback
- saturating of some groups – feedback overload
- exclusion of others
- a lack of parity of participation

Professionals: biased patient sampling
- ‘regulars’
- particular social or cultural conventions
- exclusion of patients based on inappropriate patient feedback tools
- health status & assumed capacity
Patients are not the same
  ◦ feedback platforms should reflect this
  ◦ allowing all patients to contribute

It’s not about capacity
  ◦ more about opportunity
  ◦ and availability of appropriate tools
  ◦ existing methods are restrictive

It’s about feedback
  ◦ works both ways
  ◦ feedback loops
  ◦ co–production
Repercussions & Anonymity
◦ Especially with negative feedback
◦ Both patients and professionals (including students) can fear repercussions

Equal opportunities & safe processes
◦ to achieving inclusivity and diversity in PPI in health services delivery, education, research and regulation
Recommendations:

- work towards a strategy for the collection of feedback by patients and the public across the continuum
- define precisely what it is designed to (and not to) achieve
- be clear about what type of feedback we are talking about at any given time and for any given purpose
- raise awareness of these distinctions and the opportunities and tools required
- develop accessible guidance for professionals, (including students), patients, service users and carers and members of the public
Any Questions?

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