Patient Narrative Project: Your Voice Matters Pilot

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We ALL have a bit of the ‘Big Picture!’
"I am on oxygen for 24 hours a day. I suffer from COPD and a leaking valve. I am on 15 tablets a day and inhalers. Last year I was in hospital 8 times. This year so far not once since last October and I must credit my own doctors and myself recognising early symptoms of chest infections. And I must give credit to my GPs for extending my treatment in the community."

"My COPD Life Over the last six months I have to say life with COPD is leaving me less and less able to do things for myself. I find our pathway in our Hospital is very good and so is our outreach team but I find that some Doctors will just say you have an infection I hate having to repeat one what brought me to A&E. I feel like saying just look at my files and them sometimes you are told they can’t be found and start a new one and have to repeat me over and over again. I feel our GP are fed up looking at me cause I have to go so often and then it just antibiotics and steroids and if no better you know what to do. And I have carers to help me but the company is so hard to deal with from I started getting carers I have had 34 carers come into my home and as tomorrow I don’t know who I will have in the morning. I fell the HSE should look into this company as the staff keep leaving so that is saying something about this company how the carers are been treated. I all so think we should have a respiratory ward in X and if we had one our stay in hospital would not be as long in most cases."
...we will deliver care around the individual patient and service user and put the patient at the heart of what we do. We will do this by developing a modern model of integrated care across our hospital and community services ...” (HSE Corporate Plan, 2015 – 2017)

“Person centred; care that is respectful & responsive to individuals’ needs and values and partners with them in designing and delivering that care” (HSE Framework for Improving Quality in our Health Service, 2016)

Hearing Service Users’ experiences and expectations of health services “...there is a need for a clear articulation of the benefits to patients, service users and carers, backed up by regular and detailed assessment of their experience...” Goodwin et al., 2011

Patient Narrative Project

Project Goals

Quality Goals

Definition of Quality within the Irish Healthcare System

The Patient/Service User Voice

- Clear description of the expectations of Irish service users / patients and carers as they journey through health services
- Single shared definition of Person-centred Coordinated Care
- Framework to hear patient/service user experiences and use these to aid partnership driven local & national integrated care

Patient/Service User Voice in Health

Focus Groups
Listening Groups
National Patient Experience Survey
National Patient Forum
Local service questionnaire and surveys

Patient Narrative Project

 descriptors and definition of PCCC from perspective of service users in Ireland.

Descriptors and definition of PCCC from perspective of service users in Ireland.

Frameworks to hear and use patient voice to guide design and delivery of ICPS.

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Tools for co-design from patient experience.
Progress framework to BAU
Measures of PCCC

Patient Representative Organisations
Patients / Families / Service Users / Carers
HSE / Dept. of Health
HSE Programme Managers / Service Providers
Quality, Safety & Service Improvement in CHO & HG Community Interests etc.
A Framework to Enable Co-Design and Co-Production in the Design and Delivery of Integrated Care

**Influence**
- Focus Groups
- Patient/Service User Voice in Health
- National Patient Experience Survey
- Local service questionnaires and surveys

**Design**
- Definition and Description of Person-Centred Coordinated Care
- Patient Narrative Phase 1

**Listen**
- When you change the way you look at things, the things you look at change.

**Analyse**
- Results Workshop: service Users/patients and staff analyse together to identify priorities and improvements
Your Voice Matters: Process Overview

Jan – May 2017

Patients, service users, carers and family define ‘Person-centred Coordinated Care’
Collaborative working: IPPOSI, UCD & HSE

June – July 2017

Your Voice Matters Survey Development
Test, review, feedback from patient/service user, consultation with National Adult Literacy Agency (NALA)

Sept – Nov 6th 2017

Your Voice Matters Survey Live
Target engagement with ICP – Older Persons and ICP – Chronic Conditions, Age Friendly Ireland, IPPOSI, patient organisations related to chronic conditions, HSE staff, vulnerable communities
Access: online, paper copy, mobile app, independent, data gatherers

Nov 13th 2017

Your Voice Matters Results Interpretation Workshop
60 HSE staff and patients review, discuss and interpret results at national level; key themes and areas for action!
Survey tool reviewed and revised

Jan 2018 onwards

Your Voice Matters Pilot Report and Next Steps
National data, ICPs, CHO, case studies, action plans, staff feedback, patient feedback
Vision for 2019, Your Voice Matters Governance
Now please think about your story ... what matters?

Q1. In this experience, I was treated as ...

☐ N/A

A human being

☐ N/A

A number

A burden

My symptoms and treatment

☐ N/A

My quality of life

My longer term plans

Q2. In this experience, the health staff talked to me most about ...

About the health setting ...

(Please tick all the boxes that apply to where the experience happened)

☑ Ambulance Service
☑ Community Centre
☑ Community Hospital
☑ Day Care Centre
☑ Emergency Department
☑ GP Surgery
☑ Health Centre/Primary Care Centre
☑ Hospice
☑ Hospital Clinic
☑ Hospital Ward
☑ Mobile Health Unit
☑ Nursing Home/Residential Home
☑ Outpatient/Residential Home
☑ Own Home

About the health staff involved in the experience ...

(Please tick the boxes that apply)

☑ Audiologist: tests hearing
☑ Case Manager: co-ordinates care of a patient
☑ Catering staff: prepare and serve food
☑ Chaplain: pastoral or spiritual care
☑ Consultant: a specialist doctor
☑ Dentist: checks and treats teeth
☑ Dietitian: provides information about food and diet
☑ GP
☑ Healthcare Assistant: works alongside nurses and doctors
☑ Home Help: helps in your home with daily tasks of living
☑ Hospital Doctor
☑ Hospital Nurse
☑ Midwife: specialist nurse for pregnancy and birth
☑ Occupational Therapist: helps people to be as independent as possible with everyday activities, school and work
☑ Ophthalmologist: specialist eye doctor
☑ Optician: tests eye sight and prescribes and fits glasses
☑ Paramedic: first person to an emergency often in ambulance
☑ Pharmacist: prepares, supplies and provides information about medicines
☑ Physiotherapist: helps people with physical difficulties to get better movement
☑ Podiatrist: helps with problems with feet
☑ Porter: helps patients move around a hospital
☑ Psychologist: helps with changes in thinking, mood and behaviour
☑ Public Health Nurse or Community Health Nurse
☑ Radiographer: trained to take and read X-rays, CT scans and MRI
☑ Radiologist: specialist doctor to take and read X-rays, CT and MRI
☑ Secretary or Receptionist
☑ Social Worker: supports families and children who need help
☑ Speech Therapist: helps with talking, understanding and eating and drinking
☑ I don't want to say
☑ I wasn't sure who the person was
Your Voice Matters: Listen

Survey Available:
- Hard Copy
- Online
- App on Smart Phone

Individual supported and trained peer supported completion of survey

Engagement with local support groups, community groups, local services.
Engagement with local health and social care services.

Promotion via social media (Twitter, Facebook, conference presence and presentations, HSE Broadcast email)
Your Voice Matters: Listen

Focus on people who do or may use the ICP-OP & ICP-CD.
Engaged with HSE and non-HSE patient groups and through community and hospital services for older people and people with chronic conditions.
Engagement at three levels: broad to specific supported engagement.
# Your Voice Matters: Listen

## 584 respondents

| Patient/Service User, Carer, family | 52% respondents patients/service users  
45% respondents carers, family or friend  
3 & ‘other’ |
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Ethnicity</td>
<td>84% respondents Irish, 4.1% Irish Traveller Community, 6.3% another white background, 4.1% other backgrounds</td>
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<tr>
<td>Gender</td>
<td>63.8% Female and 32.7% male. 4.4% preferred not to say and no transgender respondents</td>
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<tr>
<td>Age</td>
<td>82% respondents between 26 and 84 years old, 20.3% between 46 and 55 years</td>
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<tr>
<td>Health Condition</td>
<td>Respondents had a range of health conditions with respondents selecting between 1 and 13 conditions; 2 health conditions selected most</td>
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<tr>
<td>Cultural Needs</td>
<td>27% respondents reported cultural needs met, 60% reported ‘not an issue’, 13% reported ‘to some extent’ and 2 respondents reported ‘not met’</td>
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| Healthcare Setting                  | Many respondents selected more than one setting  
Hospital settings were selected most (ED 299, hospital ward 240, hospital clinic 150).  
Of community settings, GP was selected 209 times, own home 88 times, day care centre 54 times,  
health centre 45 times, nursing home/residential home 20 times and hospice (1) |
| Healthcare Staff                    | Many respondents selected more than one member of healthcare staff.  
Hospital nurse, hospital doctor and consultant were selected most by respondents, 335, 313 and 282 respectively  
In the community, GP was selected most times (215), Public Health Nurse (67) and Community Nurse (47) |
| CHO Area                            | CHO 1: 59  
CHO 2: 70  
CHO 3: 67  
CHO 4: 91  
CHO 5: 139  
CHO 6: 50  
CHO 7: 117  
CHO 8: 51  
CHO 9: 83 |
What does it mean?

• Many survey respondents are not experiencing person-centred care
• Many staff are not successfully conveying empathy, dignity and respect to patients
• Conversations between health staff and patients focus mostly on the medical condition and not the impact of this on the person and his or her life
• Decisions about treatment are based most on health staff knowledge and health service resources, with limited input from what the patient wants
What does it mean?

• Many people are not experiencing co-ordinated care during their health and social care experiences
• 2 out of 3 people have experienced disruption when trying to have their health and social care needs met
• 2 out of 3 people do not experience team decision making
• ¼ of people do not know who made decisions about their treatment and ¼ don’t know what’s happening after the experience was over
• For more than half of people follow-up is happening
• Not knowing what is happening is disempowering for people
What does it mean?

- The largest cluster of experiences are indexed towards accessing services after an uncomfortable delay. Keeping patients informed during the waiting period is essential as well as increasing access to services.
- Keep the patient perspective at the centre when measuring the impacts of services.
- It is positive that over 50% of people got information that was practical and/or easy to understand.
- Over a quarter of people got information from healthcare staff that was conflicting.
- Highlights the importance of understandable, practical information to being in control of one’s health.
## Your Voice Matters: Analyse

### PCCC Domains

<table>
<thead>
<tr>
<th>Empathy, Dignity &amp; Respect</th>
<th>Journey through Healthcare</th>
<th>Partnering in Decision-Making</th>
<th>Team Work / Co-ordinated Decisions</th>
<th>Access to Health Services</th>
<th>Information Received</th>
<th>Most Important Aspect</th>
<th>Accountability</th>
</tr>
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### Key Principles for Integrated Care Success

#### Empowered patients, service users and families
- 80% of experiences indicate that decision-making in health and social care is most influenced by HSE resources and staff skills and knowledge, not what the patient wants.
- 13% of experiences were indexed towards person-centred conversations; looking beyond medical condition and needs of the person presenting.
- 55% of experiences were indexed towards receiving information that was easy to understand and practical, and 45% indexed towards receiving ‘conflicting’ information from staff.

#### Competent, well-informed empathetic workforce
- 46% of experiences indexed towards being treated as a human being; empathy highlighted
- In 60% of experiences accountability and follow up happened

#### Co-ordinated journey and joined up working
- 33% of experiences were indexed towards experiencing ‘smooth’ journey
- 25% of experiences were indexed that they ‘did not know who made decisions’ in their healthcare journey

#### Access to services:
- 18% of experiences indexed that services were accessed ‘promptly on time’ and 38% indicated that services were accessed ‘after an uncomfortable delay’

### Lived Experience of Patients/ Service Users and their Families

#### Your Voice Matters Pilot December 2017 N=584

<table>
<thead>
<tr>
<th>Key Areas for Improvement &amp; Recommendations</th>
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<tr>
<td>1. Clear communication and information; interpersonal, between staff and across locations and teams, information accessibility including literacy, interpreter access</td>
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<tr>
<td>2. Collaboration and partnership working between service users and staff; expertise on both patient and staff sides, patient seen as a person and active participant in health, open well-informed staff</td>
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<tr>
<td>3. Co-ordination of and access to services: working across and within health and social care boundaries, information while waiting for services, staff well-informed about services</td>
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**Recommendation**

Implementation of integrated care planning and audit of same to establish the extent to which individuals have choice and control within their care and treatment as in ICP-OP and ICP-CD documentation.
Your Voice Matters: Analyse

Ideas for Improvement

Acts of Kindness

- Improve physical accessibility in clinics and hospitals
- Address needs of specific groups of people in community e.g.
- Better spread of services nationally
- Clear specific pathways for specific health needs
- Have case manager or coordinator
- Use technology to improve services
- Provide supportive environment for staff
- Better community services after discharge
- Have more time with healthcare staff
- Develop care plan with patient and family
- Access to interpreters (sign language, literacy, additional languages)
- Keep patient & family informed when waiting
- Improve Emergency Department experience
- Improve staff skills
- More services
- More staff
- Communication between staff and health settings
- Include Patient & Family views
- Other specific ideas
- Shorter waiting times
- Staff interpersonal skills (e.g., empathy, listening)
- Clear, consistent information and explanation

- Respected dignity
- Non-judgemental
- Used person's name
- Smiled
- Apologised
- Made time to talk
- Stayed after shift
- Involved person in decisions
- Put person at ease and comfortable
- Helpful
- Support from another patient, family or agency
- Other
- Polite and pleasant
- Considerate of personal circumstances
- Provided reassurance
- Really listened
- Concerns about components of services
- Nothing kind
- Competent in tasks
- Showed empathy
- Followed up and tried to coordinate care
- Gave clear information and explanation
What needs to change so that there are more stories in the centre of this triangle?

- Co-ordination
- Care-planning
- Communication
- Partnership
Your Voice Matters: Co-design & Co-production

**National**
- Design and development of Integrated Care Programmes (Older Persons, Prevention & Management of Chronic Conditions, Children, Patient Flow)
- Baseline of how people experience services
- National programmes and frameworks
- Evidence-informed ‘Urgent and Emergency Care: snapshot in the Irish context’ which supports the HSE Transformation of Urgent and Emergency Care Project

**Local**
- Local implementation of national frameworks; local evidence informed prioritisation of actions plans for national strategy
- Local identification an planning of service improvements; local data & local workshops
- ICP-OP Pilot site Service Improvement Workshops and plans
- Contribute to the service user representative voice and progress co-design and co-production philosophy (e.g., QID patient advocacy, National Patient Forum)
Your Voice Matters: Influence and Co-produce

ICP – Older Persons Service Improvement

The cycle as to how the voice of older people collated through Your Voice Matters will be used to improve local services for older persons.

Local ICP-OP steering groups, Age Friendly Ireland and Older Persons Council provide an integrated network through which improvements can be driven.
Your Voice Matters Pilot: Conclusions

- Your Voice Matters provides a framework to enable co-production and co-design in the delivery of integrated care.

- The data from Your Voice Matters pilot provides that first check of how the journey is going from the perspective of the people who use services.

- It has the ability to provide real-time qualitative and quantitative data about the experiences of people and allow us to see the person behind the statistics.

“What matters is what gets measured ... “ (National Voices, 2017)

…..what gets measured is what matters??

Thank You