

Family Meetings at the NRH

Family Meetings



A Guide to Preparing for Patient and Family Meetings at NRH

A Guide to Meetings at the NRH for Patients, Families and Carers

You and your family are key members of the Rehabilitation Team and your input is vital. Family participation is known to improve the quality and outcomes of rehabilitation.

During your time at the NRH, you and your relatives or carers will be invited to come to meetings organised by the Rehabilitation Team.

These may be initial family meetings to get to know your particular situation, or meetings to set treatment goals, update your progress or plan for your discharge. There are often many arrangements which need to be made well in advance of your discharge, such as adaptations to your home or referrals to local community services.

- National Tertiary Neurological Rehabilitation service for Republic of Ireland – acquired brain injury, spinal cord injury and limb loss
- Brain Injury Programme has 54 beds / 220 programmes per year/150 + on waiting list
- Av age is 47years/D/C to home rate of 78%/Av LOS 82 days
- All patients are offered at least 1 family meeting with the IDT.
- Preparation and Planning involved for pts and family members – SW function
- An Information leaflet is available
- 150 staff potentially involved in family meetings which last approx. 1-1.5 hours (60% of clinical staff at NRH)
- Variety of meeting rooms/styles/times and chairing arrangements
- Increasing difficulties in arranging for relatives/friends to be present due to work, child care commitments, finances and length of time since initial injury

Research questions to be addressed:



What is the purpose and role of Family Meetings for patients and families in a rehab hospital setting?



What are patients, family member and IDT member views and attitudes about Family Meetings and their participation within this forum?



Are patients and their family members satisfied with the level of participation and control afforded to them at Family Meetings?



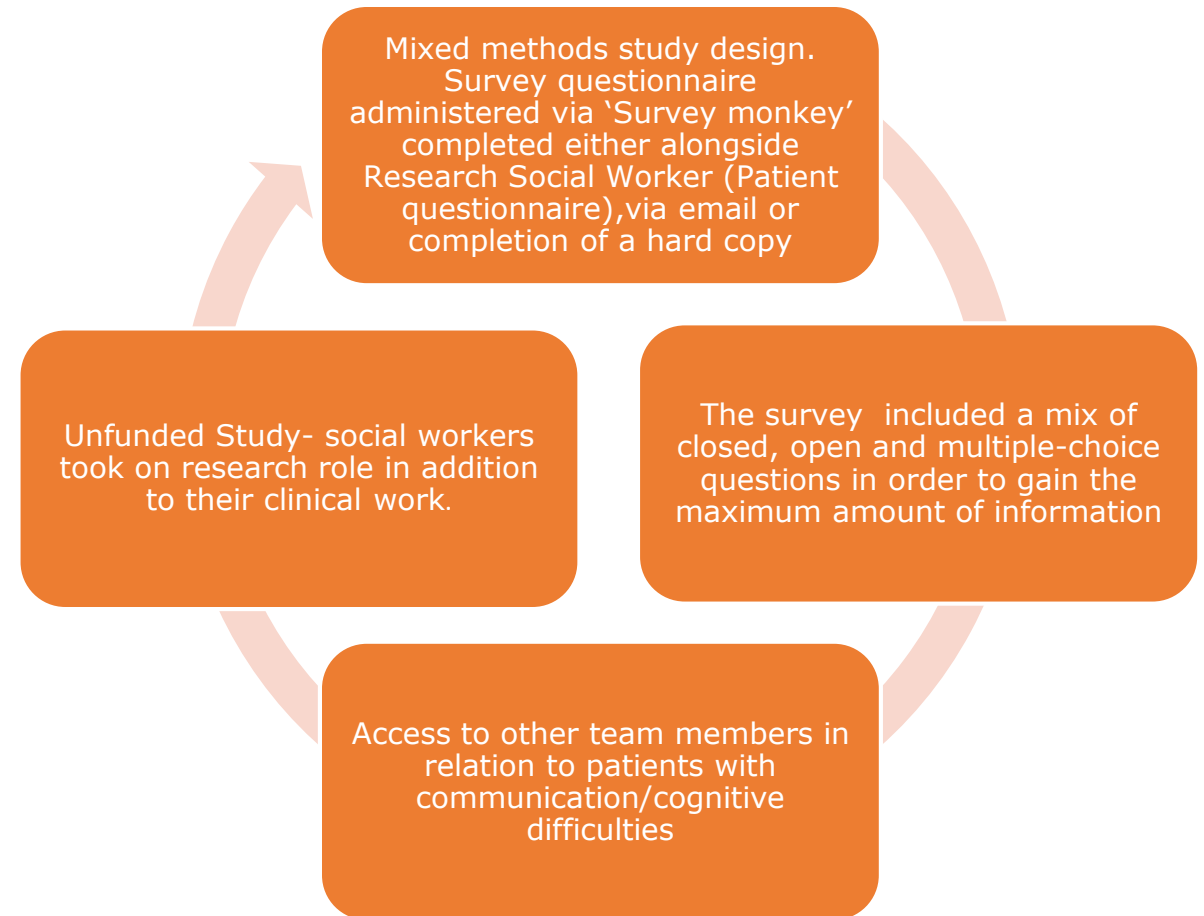
Do IDT members feel sufficiently trained in the skills required to participate in Family Meetings?



Key objectives: service evaluation, quality assurance, changes and improvements to current practices as well as increased research capacity in SW Dept

Study Design

- **Included:** inpatients of the NRH who were under the care of Spinal, ABI or POLAR service and who had been the subject of a Family Meeting.
- **Excluded:** Pt's with DOC, pt's who were assessed as unable to participate in their Family Meeting in any meaningful way due to a severe cognitive impairment and pt's who were children aged under 16 were excluded.
- The social worker who was involved in each FM acted as a gatekeeper and invited the Pt and at least one or more family members to participate in the survey.
- A member of the social work team who was *not* clinically involved with the Pt and family administered the questionnaire
- All Social Workers involved in study at some level: survey design and gave advice on practicalities



Work Packages

Work package 1(Dec 2016-April 2017): survey of all IDT teams in the NRH (N=85 / 50% response rate).

Work package 2(April 2017-December 2017): survey administered to patients by personal interview by research social worker. Patients under the care of Brain Injury, Spinal and POLAR teams who have attended a family meeting (N=74). (originally April to June and N =100)

Work Package 3(April 2017-December 2017): survey given/sent to a minimum of one family member of each patient who has attended a family meeting (N=63). (originally April to June and N=100)

Family members rarely used the online method – questionnaires had to be inputted manually!

Brain Injury Programme (BIP) respondents



51.35% (n=38)
were from the BIP



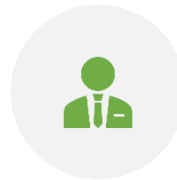
36.84% cognition
didn't affect ability
to participate in FM



50% - mild
cognitive
impairment



13.16% -
moderate
cognitive
impairment

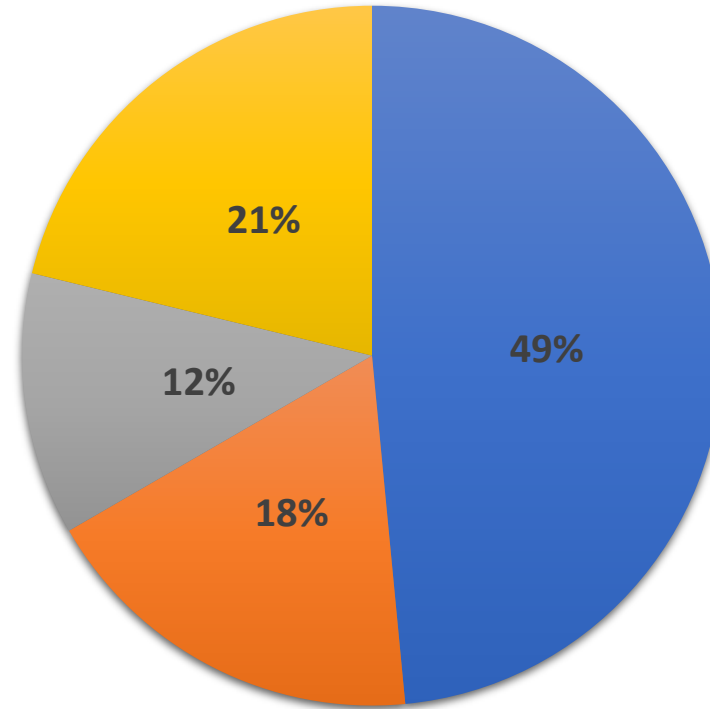


52.17% of staff
who responded
were based in the
BIP



54.69% family
respondents were
in relation to
family meetings on
the BIP

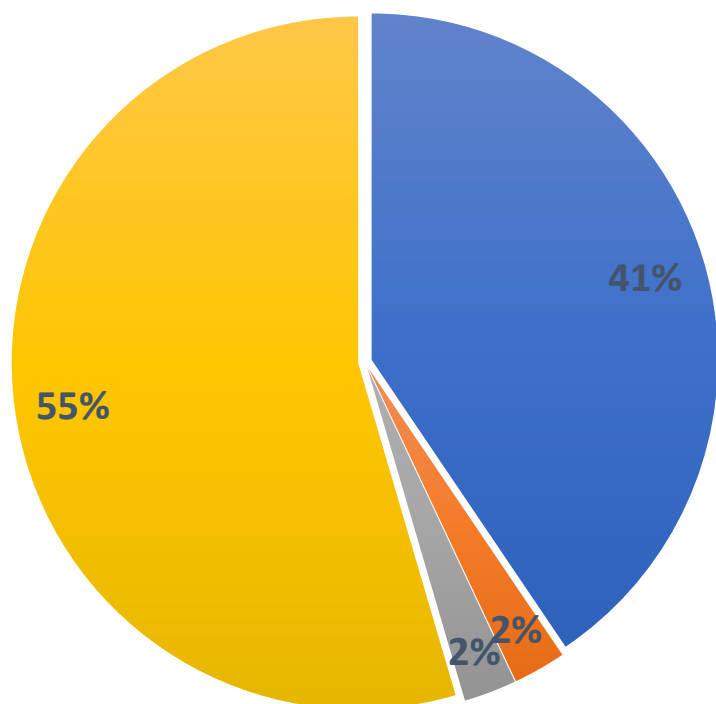
Family/Carers present (BIP)



■ Spouse/Partner ■ Siblings ■ Children ■ Parent

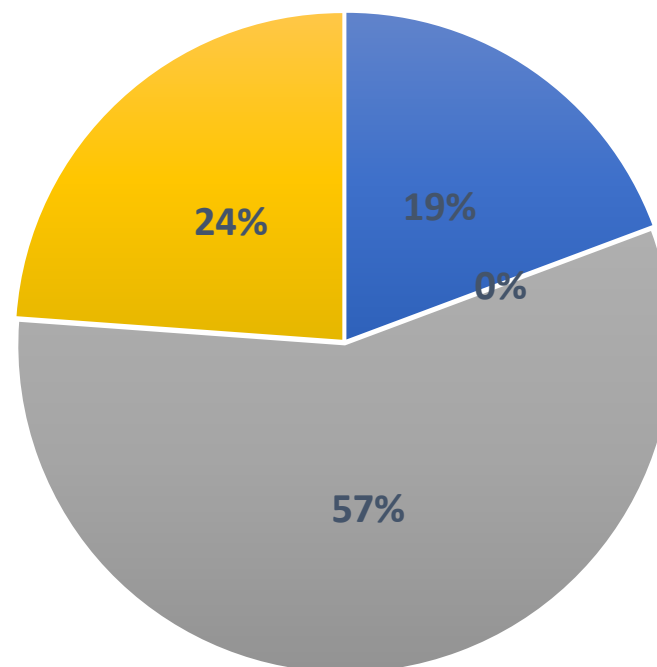
Did anyone explain what the meeting was about beforehand?

Patient



■ Yes ■ No ■ Unsure ■ Don't recall

Family



■ Yes ■ No ■ Unsure ■ Don't Recall

What information would you have liked before the Family Meeting?

Patient surveys

- A specified person to tell you about the meeting – people kept saying *“you know you have a meeting”* but I didn’t know
- Pre-meeting information and enough time to invite family
- *“I would have liked to have been prepared to answer... to know the questions that were coming upnot to have 8-10 people “firing questions at you”*
- *“It felt like getting my leaving cert results”*
- *“Something to drink”*
- Not to be kept waiting half an hour

In the meeting?

- Explanation of the condition
- More information about NRH follow up and post discharge appointments
- *“What I am going to do for the rest of my life...”*
- More about carer support
- Some people missing e.g. physio, consultant

Family member surveys

- What to expect
- Who to contact later after some of the things said had been processed
- A short agenda to outline the steps of the meeting might be helpful
- We were reasonably prepared for the meeting but not for the formal “case conference” set up – for example the power point with all the patient’s information
- To expect the delay

In the meeting?

- A more conversational style

Did you feel that hospital staff prepared you well enough for the meeting?

Patient

- 71.05% Yes
- 26.32% No
- 2.63% Don't recall

Family

- 82.86% Yes
- 14.29% No
- 2.85% Don't recall

Inclusion – Patients and Families Brain Injury Programme

Did you feel you could ask any questions you had?

- | Patient | | Families |
|----------------------|-----|----------|
| • 91.89% | yes | 97.14% |
| • 2.7% | No | 2.86% |
| • 5.41 comments only | | |

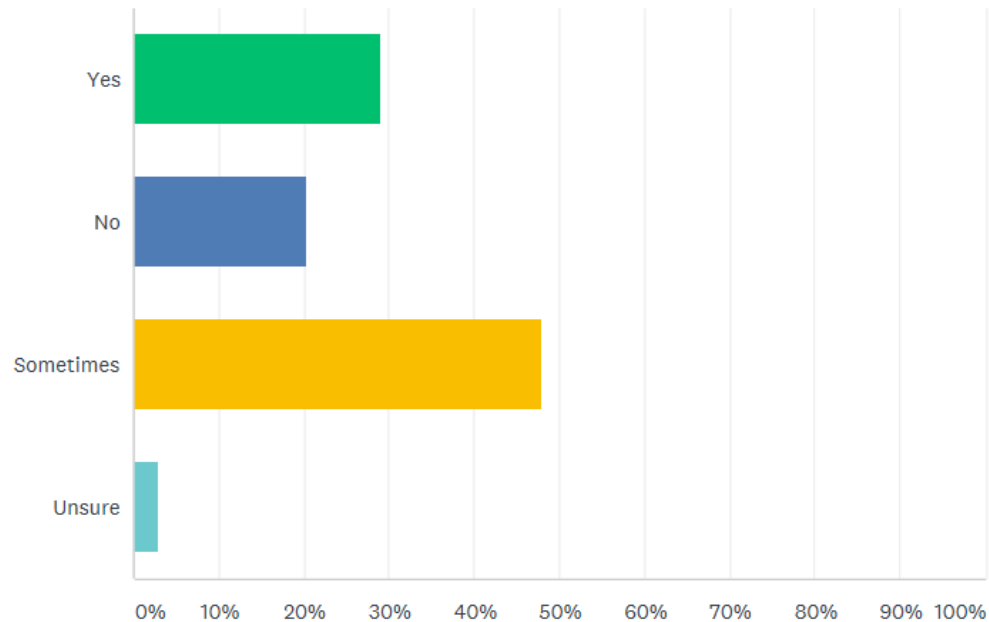
When asked if they felt part of the discussions, 100% of BIP patients responded 'Yes'

Did you feel involved in decisions made?

- | Patient | | Families |
|----------|--------------|----------|
| • 71.05% | yes | 54.53% |
| • 15.79% | No | 9.09% |
| • 13.16% | Sometimes | 27.27% |
| • 0% | Don't recall | 9.09% |

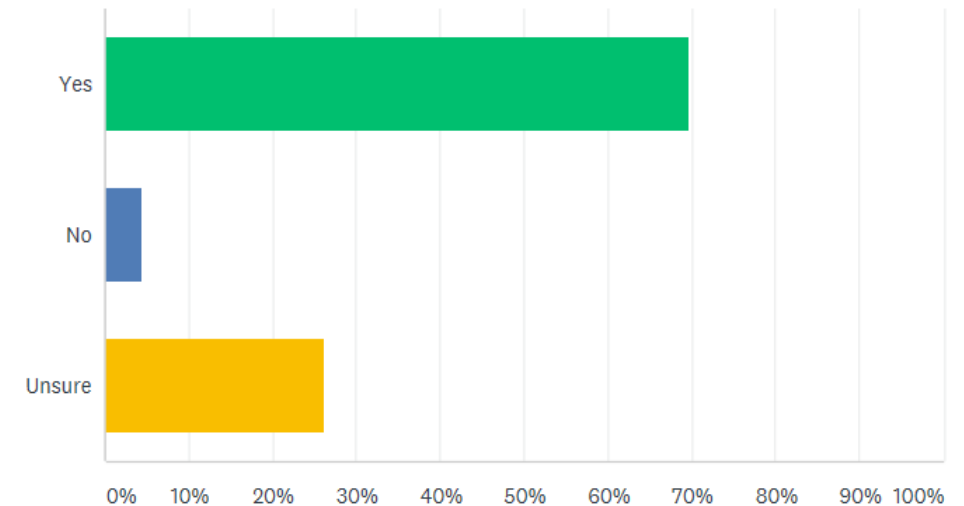
Do you feel that patients are included/involved enough in Family Meetings?

Answered: 69 Skipped: 16



If a patient doesn't have full decision-making capacity, are there differences in how these patients are included/involved in Family Meetings?

Answered: 69 Skipped: 16



Patient

- 86.84% Enough information
- 2.63% Too much information
- 0.53% Not enough information

Amount of information given at the meeting?

Family

- 82.86% Enough information
- 17.14% Too much information
- 0.0% Not enough information

Did you find the meeting upsetting or distressing at any stage?

Patient

- 15.79% Yes
- 73.68% No
- 10.53% Sometimes
- 0% Unsure

Family

- 11.76% Yes
- 50% No
- 29.41% Sometimes
- 8.82% Unsure

If you were upset – what caused it?

Patients:

- *“Worried about what to expect – what the family would say”*
- *“The fact they were stressing out my limitations with my wife beside me....plans that I have in my head were shot down. I’ve been making small improvements and my wife is happy with them”*
- *“having my family to be told the facts of what I had been through”*
- *“If goals were not going to be achieved”*
- *“It was the worse experience....very negative and stressful....going over information I already know – it just brought it back”*

Families:

- *“We were coming to terms with the new reality..”*
- *“Made me realise how much as a family unit we have been through in the last 5 months”*
- *“The team in a very gentle way made us take on board the true outcome that we had to face yet, which made it very hard for me”*
- *“It was upsetting hearing Dad’s expectations for discharge versus recommendations from professionals”*
- *Realisation that it will be a long and difficult recovery.*

Was there anything talked about which you didn't understand during the Family Meeting?

Patient

- 2.63% Yes
- 81.58% No
- 13.16% Sometimes
- 2.63% Don't recall
- (SCI group – 19.23% said yes)

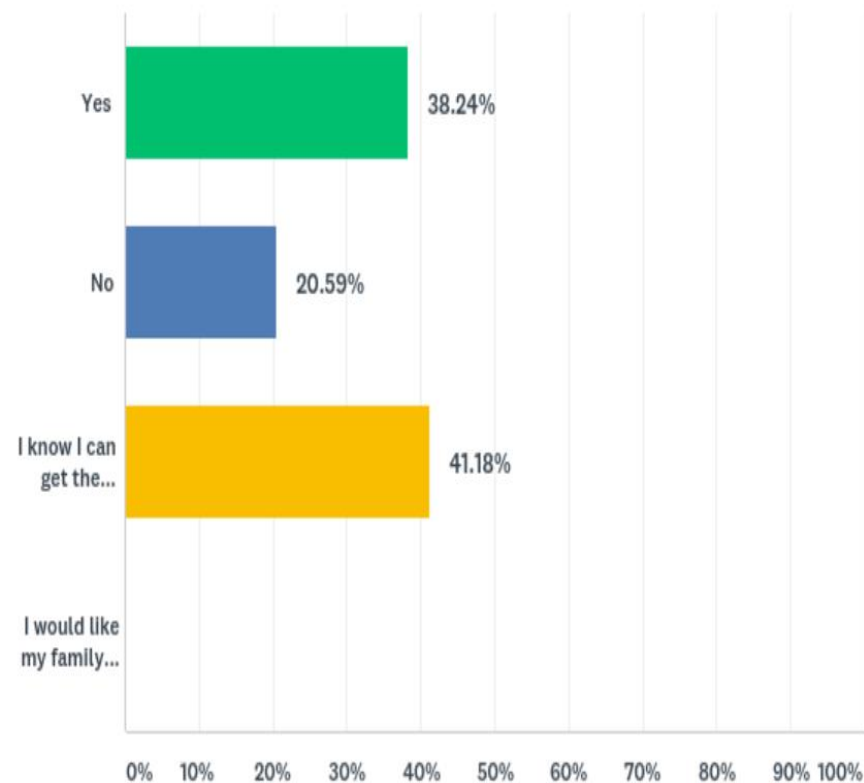
Family

- 5.71% Yes
- 68.57 % No
- 23.71% Sometimes
- 0% Don't recall

“...medical terms used...my wife is a nurse- we had to look up the term but she could explain it to me...I didn't stop to ask as I knew that my wife would explain it to me after the meeting”

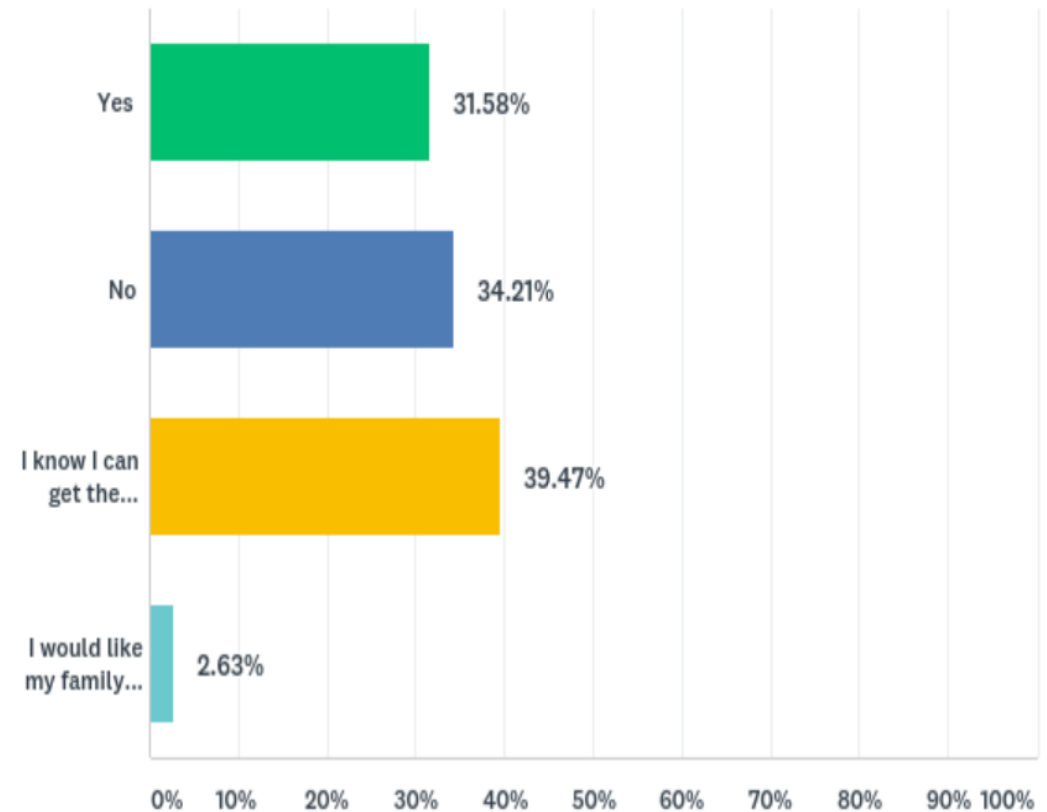
Would you like to have been given your own written copy of what was discussed or decided during the Family Meeting?

Family Member Response



Would you like to have been given your own written copy of what was discussed or decided during the Family Meeting?

Patient Response



Family members' Quotes

Re: asking questions in the meeting and the room arrangements

".....seating arrangements were quite formal – can be daunting for first time attendees"

".....we were regularly invited to provide feedback throughout the meeting"

"room was perfect – very professional"

"...In the first meeting there was a lot of new information to take in and it was hard to take everything in and then think of questions"

".....projector behind the head of the patient not ideal but it wasn't used on this occasion"

".....was happy with the round table dynamic of the meeting. Introductions of each person at the beginning most helpful"

".....where do I start with this one?? Awful setting, awful environment. Would have been so much nicer if it had been in a room with couches and no big formal table, Power Point etc"

"(room was) a little cramped"

Patient Suggestions for Improvements

- Bring everyone into the room at the same time
- Don't have people waiting outside – it's intimidating
- Help prepare patients e.g. to have a list of what they wish to discuss ready – perhaps a pre-meeting
- *“Stay short. Get all the key points in. Don't be too long so you don't fall asleep during it”*
- More post exit information and advice
- A written copy of what was discussed
- Suggestions about the room/seating/the long table
- Ask the patient how they are doing
- Tell the patient which staff will be present – *“it's only fair”*
- Clarity re expectations/a template of suggested questions or pointers – *“what do my family need to know that I can't tell them”*
- Meeting was too early for people travelling from the West of Ireland
- A second meeting might be helpful
- Be clear who the chair is
- Make them more friendly/less formal/more relaxed *“tell people that they are not in trouble....remind people to breathe”*
- More privacy – *“might have things I don't want shared with my wife”*
- Would have liked (different staff) present/the whole team – one person wanted less people

Family Member Suggestions for Improvements

- More free flow conversation/less formal environment
- Input from the patient at the beginning – how they feel they are progressing
- Patients need to feel heard – ask them how they are getting on, what is frustrating them, what is going well
- Agenda/minutes/outcomes of the meeting
- Solution focused rather than looking at barriers
- Better seating/room arrangements (esp. long table)
- Patient coming into the room last means it's intimidating for them
- More time for family members (patient joined later)
- More focus on recommendations/strategies on discharge
- A questionnaire about topics that are relevant that we might not have focused on
- Families writing things down in advance
- More options on times/dates
- More notice
- To have relevant people present
- More information on the condition/what to expect and what to look
- *“Remind staff that though they may be well used to these meetings, it is nerve wrecking for patients and families”*

Blocks and Enablers

(Staff
Survey
Results)

Blocks

- Poor pre-meeting preparation
- Staff arriving late/key IDT members not present
- Poor communication and use of technical jargon
- Differences in opinion between IDT members re: discharge plan
- Pt/Family receiving new information which they have not been prepared for.
- Pt/Family feeling their questions haven't been answered/not listened to

Enablers

- Significant pre-meeting preparation
- Expectations(Pt and Family) managed
- Team Consensus and plan agreed
- Skilled Facilitation
- No interruptions
- Comfortable, informal meeting room
- No new significant information being shared and clarity on supports which can be accessed.

Where to next?

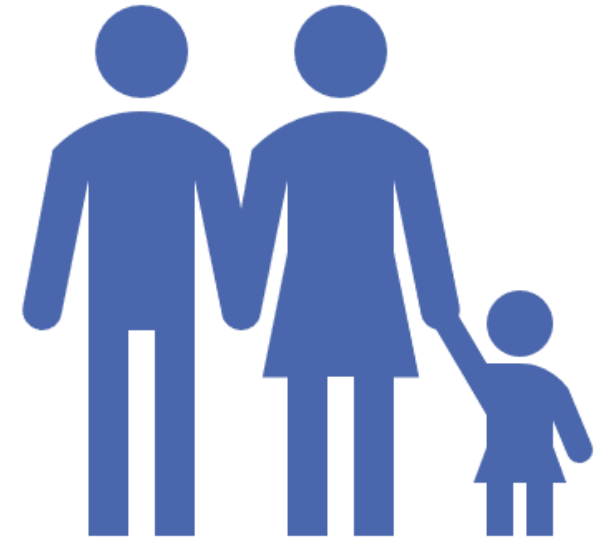
- Improvement and changes
- Patient and family involvement (co-production/PPI)
- Templates and Training – 76% of staff felt this would be helpful
- Review and re-audit
- Capturing people who have more challenging communication difficulties/advanced cognitive impairment



Closing thought

'...the skill and effort that we put into our clinical communication does make an indelible impression on our patients, their families and their friends. If we do it badly, they may never forgive us; if we do it well, they may never forget us.'

(Buckman,2002)



Thanks to...

- NRH Staff, Patients and Family Members who participated in the study
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