Patient and Public involvement (PPI) work alongside Advisory Group

First meeting of project advisory group - agenda

DATE: MONDAY 14TH DECEMBER
VENUE: NUFFIELD ORTHOPAEDIC CENTRE, WINDMILL ROAD, OXFORD
TIME: 11.00 – 14.30

TOPIC	MEMBER	START	FINISH
WELCOME AND INTRODUCTION FROM THE CHAIR	CHAIR, MEREDITH NEWMAN (MN)	11.00	11.10
GROUP INTRODUCTIONS	CHAIR & MEMBERS	11.10	11.25
OVERVIEW OF PROJECT	FRAN TOYE (FT)	11.25	11.50
WHAT IS META-ETHNOGRAPHY?	KATE SEERS (KS)	11.50	12.10
STRUGGLING TO BE ME – THE FILM	FILM VIEWING (MEMBERS)	12.10	12.30
LUNCH: 12.30-13.00			
HOW DO YOU ANALYSE QUALITIVE RESEARCH – A SEASONAL ACTIVITY	ALL MEMBERS	13.00	14.00
PROJECT ORGANISATION	KAREN BARKER	14.00	14.15
THANKS AND GOODBYES	CHAIR, MN	14.15	14.30

Second meeting of project advisory group

DATE: 24th June 2016
VENUE: NUFFIELD ORTHOPAEDIC CENTRE, WINDMILL ROAD, OXFORD
TIME: 11.30 – 15.30
Apologies Jane and Jens

TOPIC	MEMBER	START	FINISH
WELCOME AND INTRODUCTION FROM THE CHAIR	CHAIR, MEREDITH NEWMAN (MN)	11.30	11.40
OVERVIEW OF PROGRESS	FRAN TOYE (FT)	11.40	11.55
INTRO TO AFTERNOON	MEREDITH (MN)	11.55	12.00
LUNCH: 12.00 – 12.30			
INSTRUCTIONS FOR ACTIVITY	FRAN TOYE (FT)	12.30	12.40
ANALYSIS OF POSTCARD THEMES	ALL MEMBERS	12.40	2.00
TEA		2.00	2.15
SYNTHESIS AND FEEDBACK	15 MIN/GROUP 20 MINS SYNTHESIS	2.15	3.20
GOODBYES AND THANKS (DONM)	FRAN TOYE (FT)	3.20	3.30

Final meeting of project advisory group

DATE: FRIDAY 13TH JANUARY
VENUE: BOARD ROOM, NUFFIELD ORTHOPAEDIC CENTRE, WINDMILL ROAD, OXFORD
TIME: 10.30-3PM

TOPIC	MEMBER	START	FINISH
WELCOME AND INTRODUCTION TO DAY	CHAIR, MEREDITH NEWMAN (MN)	10.30	10.45
PROGRESS SINCE LAST MEETING	FRAN	10.45	11.10
INTRODUCTION TO THE FILM	KATE	11.10	11.30
BRAINSTORM SESSION – DISSEMINATION	FRAN	11.30	12.00
LUNCH: 12.00-12.45			
OUTPUTS – WORKSHOP	FRAN TO INTRODUCE ALL	12.45	13.30
FEEDBACK FROM EACH GROUP	MEREDITH	13.30	14.30
THANKS AND GOODBYES	CHAIR, MN	14.30	14.45

Example of analytic work in advisory group

Group 1

1. Cultural 'lens' gives a sceptical view of chronic pain: a tension between judging and knowing you shouldn't judge a book by its cover. 2 areas of scepticism a. personal scepticism from moral framework and b. scepticism because no physical cause found
2. Feel under skilled in chronic pain management and learn the craft on the job
3. Navigating the geography of the relationship between clinician and patient is very hard sometimes [note – who writes the map]
4. Test and investigations have multiple roles that are not always clinical
5. Guidelines also have multiplicity of function not always clinical.
6. Value of team work. Break down professional barriers and respect each other's work
7. The need to refer on to someone else. We don't work in isolation [me, us, we, you] but what do they offer that we can't.
8. Cost to self of 'defensive medicine' : a. personal emotional impact and b. accepting uncertainty
9. Dichotomy of dualistic biomedicine and holistic embodied

Group 2

1. Time it takes
2. Lacking learning (experience, teaching)
3. HCP afraid of giving psychosocial explanation. Focus on biomedical even if it doesn't fit CP
4. Guidelines and tests useful to a point
5. Respectful team working
6. Finding common ground hard work
7. Failing to find common ground
8. Advocate at a cost
9. Pain not real
10. Accept uncertainty (k2) dichotomy with exhausted overwhelmed (F1) – links to 3 (fear of giving psych explanation
11. [tension in clinician a. need to see person holistically BUT b. afraid of implying holistic origin – rock and a hard place]

Group 3

1. Guidelines – 'take them or leave them' – evoking an authority that is not in the room
2. Tests – defensive medicine/cover back
3. Cost to self
4. Learning the craft lack of skill training
5. Don't judge a book by its cover
6. Pain-professionals team
7. Navigate professional and patient expertise; moving towards a shared a agenda
8. Sitting alongside
9. Continuum biomed and psychosocial
10. Drivers for decision-making

Common themes from advisory group analysis

1. This describes a cultural lens for seeing chronic pain that provides a sceptical view of chronic pain. I know I shouldn't judge a book by its cover but sometimes I do this. I focus on the biomedical, even though it does not fit because of this scepticism. My patient might react badly and also I am personally struggling with the psychosocial approach as a clinician. If there is no diagnosis this creates scepticism. I am part of this culture.
2. My clinical education has not given me the skills for this. Learning is from hands on and personal experience; a craft
3. Navigating the geography between patient and professional can be treacherous but it underpins therapeutic care. I sometimes fail to find common ground. Need to find a shared agenda where we can sit alongside the patient
4. Tests and investigations have a multiplicity of function that is not always clinical. At times there is a need to be defensive in the world we live in.
5. Guidelines evoke a power that is not in the room
6. Pain management is a collective endeavour. We need to break down professional barriers; value and respect our colleagues. Even though at times I have ambiguous feelings about other professionals in the frame and have difficulty accessing what I need I cannot work in isolation
7. I get to know and SEE my patient at personal cost. The emotional burden is both personal and professional (I am failing)
8. There is a dichotomy between dualistic medicine and holistic embodied medicine that challenges me.