



# Understanding patients' perspectives influencing participation within EQUAL study in UK – A Qualitative study.



Anirudh Rao<sup>abc</sup>, Fergus Caskey<sup>abc</sup>, Yoav Ben-Shlomo<sup>c</sup>, Lucy Biddle<sup>c</sup>

<sup>a</sup>UK Renal Registry, Bristol, UK; <sup>b</sup>Southmead Hospital, Bristol, UK; <sup>c</sup>School of Social and Community Medicine, University of Bristol, UK,

## 1. Background:

- Recruitment into studies can often be problematic with older frailer patients and those with multiple co-morbidities less likely to agree to participate.
- In the pilot study of EQUAL only 1 in 3 eligible patients attending hospital clinics agreed to participate.
- Non-participation can not only affect a studies internal validity but also its external validity (generalizability).

## 2. Aim:

To understand issues those underpin patient recruitment to the EQUAL Study.

## 3. Methods:

### 3a. Study Sites:

- Three of the 10 EQUAL recruitment sites in the UK (Bristol, Salford & Oxford)
- Selected according to recruitment data from the first few months of the study, to reflect centres with high and low recruitment rates.

### 3b. Participant sampling:

- Agreed and did not agree group
- Purposive sampling to achieve maximum variation: Age (65-74 & 75 above) and Co-morbidity (0-2 & ≥3)
- Exact numbers in the groups and the substrata was determined according to the number required to achieve a consistent understanding across a diverse groups.

### 3c. Data collection:

- A topic guide was used to ensure consistency.
- Participants were encouraged to raise the issues they consider important with minimal prompting.
- Probing was used to clarify salient points and encourage reflection.

### 3d. Analysis:

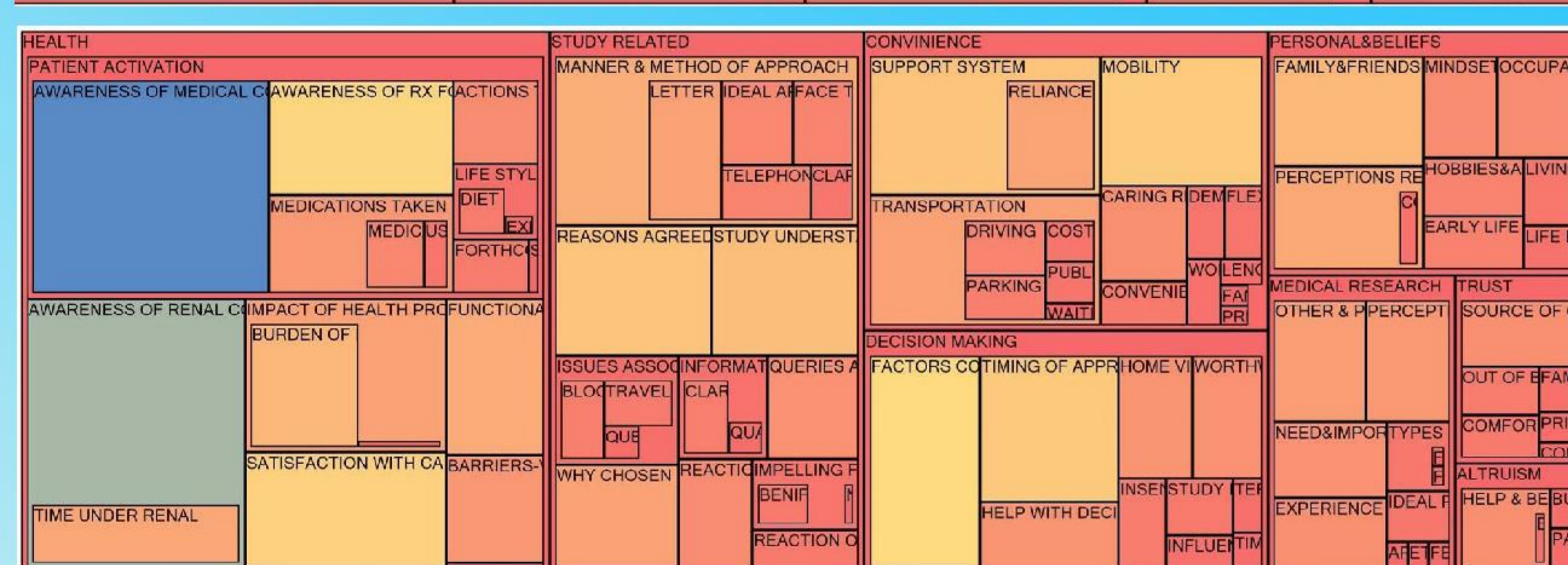
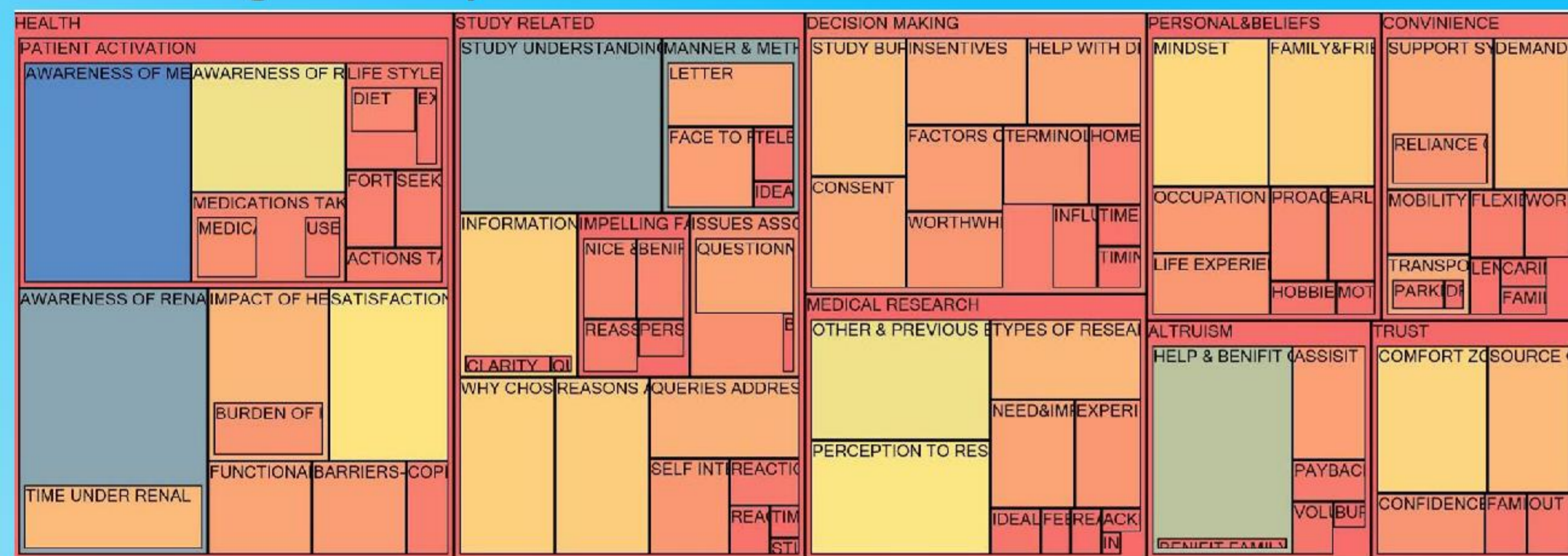
- Interviews were audio recorded and transcribed verbatim.
- NVivo software will be used to aid analysis.

## 4. Results:

### 4a. Patient Sampling:

EQUAL participation status	Agreed to participate N=17		Declined to participate N=17			
	65-74	≥ 75	65-74	≥ 75	65-74	≥ 75
Age	65-74	≥ 75	65-74	≥ 75	65-74	≥ 75
Co-morbidity	0-2	≥ 3	0-2	≥ 3	0-2	≥ 3
Bristol (13)	1	1	1	2	1	3
Salford (9)	1	1	0	4	0	2
Oxford (12)	2	1	2	1	1	2

### 4b. Coding Tree Map:



## 4b. Important themes

### 1. Trust

#### 1a. Source of Contact

"I think if Dr C... she gets on quite well with him, actually. If he had asked her on one of his visits and said, "Look, we're going to do this research, you know – would you do it?" I think that would have made a big difference. I think that would have ... she would have said, "Oh, yes, okay, it's fine." "Because, you know, you build up a relationship with ... sometimes ... obviously, you don't see the same specialist all the time, but you do build up ... you know, even though you're only seeing him for five minutes, it's surprising how you do get this sort of thing going. It's a confidence thing I suppose." EQUALQSS\_BRL\_DNA\_04

#### 1b. Comfort Zone

"I don't mind doing anything as long as I haven't got to go into the hospital." EQUALQSS\_BRL\_AGREE\_10

"Well I feel uncomfortable because as I told you I lost my wife ....I went to, to hospital so many times, you know.... over the time it brings back memories" EQUALQSS\_OXF\_DNA\_12

### 2. Study related

#### 2a. Why Chosen

"R: That's an interesting question. I've got no, I've got no uh queries about why I was picked, I was just wondering why I was picked, you know?" EQUALQSS\_OXF\_AGREE\_16

"R: No, I just thought I was just one of the millions, if you like." EQUALQSS\_BRL\_AGREE\_01

#### 2b. Self interest

"R:.....I've always had an interest in health matters and I feel that um, my input would be of use, would be, you know, I would be useful, I wouldn't be a waste of time." EQUALQSS\_BRL\_AGREE\_09

#### 2c. Reason agreed/disagreed

"R: ..... I think unless you have this inner feeling of I have a lot to be thankful for, I have received a lot of um help and so research is to give more and more help" EQUALQSS\_BRL\_AGREE\_12

"R: I was told I had kidney disease but I never realised I was in the chronic stage. I: OK and that that made you take a step back?"

R: It did yes definitely." EQUALQSS\_BRL\_DNA\_09

### 3. Personal & Beliefs

#### 3a. Family and Friends health experiences

"My heart condition is inherited, ....my father died at fifty and my brother died at forty-two and I am the only one out of three of us that has survived and that is all down to research....So you know, and sudden deaths as well." EQUALQSS\_BRL\_AGREE\_12

"She had cancer of the oesophagus, which she was treated for and she lived for another 20 years, and after that, when she cleared of having that cancer, she lost one of her breasts. So in a way, all what she'd been through, she wouldn't even watch hospital things on the television, you know, it sort of, she didn't talk about it. It might be mentioned, but that was it, we never went into deep discussions over anything like that." EQUALQSS\_OXF\_DNA\_05

#### 3b. Mind set

"I: And do you know anybody in your family whose been taken part in medical research?"

M: Not particularly no.

R: Our families don't go to hospital.

M: No (laugh). We keep well away from hospitals if we can (laugh)." EQUALQSS\_BRL\_AGREE\_10

### 4. Medical Research

"I: What are your thoughts on medical research?"

R: My criticism of the research system at the moment, that it's hit and miss. You can't do it all, I know that, but some areas are more privileged." EQUALQSS\_OXF\_AGREE\_04

"I: What are your thoughts on research?"

R: Well obviously it's a good thing, for probably younger people because they've got a chance of new things turning up and helping them to keep their health. EQUALQSS\_BRL\_DNA\_10

"R: Well, we need this research. How else do we learn?"

R: The miracles that they've performed, and it's through these kinds of things." EQUALQSS\_SAL\_AGREE\_08

## 6. Conclusion:

- Study highlights important motivation and barriers that influence participation of older patients in research.
- Future studies recruiting older adults should adopt a flexible approach to recruitment with minimal inconvenience to the older adults.

For Further information please contact Anirudh Rao at [anirudhrao@nhs.net](mailto:anirudhrao@nhs.net)

