



Deep End Public and Patient Involvement Panel: Sheffield End of 1st year report 2017/18

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General Practice at the Deep End Yorkshire and the Humber

Working at the hearts of communities are GPs who witness the effects of poverty on their patients health every day. Inspired by a group in Scotland we formed a 'Deep End' group for GPs working in the most deprived areas of Yorkshire & Humber.¹ We have held two large symposia since 2015 and numerous educational events. At meetings we found an overwhelming desire to reduce health inequity through supporting the workforce, sharing knowledge through educational activities, advocating for vulnerable groups and linking with research communities. This report is a summary of our activities to establish a 'Public and Patient Involvement Panel' funded by the Research Design Service in Sheffield over the past year and presents our ideas and plans for the future.

¹ Walton E, Ratcliffe T, Jackson B & Patterson D. Mining for Deep End GPs: a group forged with steel in Yorkshire and Humber. *Br J Gen Pract* 2017; 67 (654): 36-37.
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WHY FORM A PANEL WITH PATIENTS WHO LIVE IN AN AREA WITH THE HIGHEST IMD* SCORE IN SHEFFIELD?

It is widely accepted that an individual's position in society and income significantly impact their health and how long they live. These differences are called 'health inequalities' and have been repeatedly observed and described in the academic and political literature. The organisation 'INVOLVE' encourages researchers to involve patients and members of the public in academic work who are 'often overlooked or ignored by mainstream society'. We have established a new patient panel specifically for patients living in the most deprived areas of Sheffield which has allowed researchers to access discussions with people from communities who would fulfill this criteria, including migrant patients. Before setting up the panel we contacted the Clinical Research Office at the Royal Hallamshire Hospital and the Public Engagement Team at the University of Sheffield, both of whom informed us that there is no patient panel from this demographic. We have also searched the James Lind Alliance website who also do not have a patient partnership with this group: we saw this as an important gap that needed addressing.

WHAT DID WE DO? We have had 6 Deep End Panel discussions with researchers since November 2017. The Panel (7 patients) and Liz Walton also ran a workshop about PPI for academics at the Regional Society of Academic Primary Care conference in Sheffield in March 2018. Representatives of the Panel (2 patients) have also been attending Deep End Clinical Research Network meetings for GPs who are getting involved in NIHR research and have also attended a Deep End Educational meeting about migrant health.

RECRUITMENT initially proved more difficult than expected despite contacting community groups. However, after 2 meetings a Panel of 7 patients was established and attendance has been consistently high. We successfully recruited the panel through contacts at the British Red Cross and also through the receptionists and colleagues at The White House Surgery on the Manor Estate when we personally invited patients.

WHO WAS ON THE PANEL? 5 women and 2 men have regularly come to meetings. We have 3 patients who were born outside of the UK. All the members live in areas with the highest IMD scores in Sheffield.

*IMD = Index of Multiple Deprivation Score



The Deep End Patient and Public Involvement Panel works alongside our Deep End Sheffield NIHR Research Cluster. Patient representatives also attend our cluster meetings & are given shopping vouchers and travel costs. Sheffield CCG Health Inequalities Steering Group has recently offered to fund the Patient Panel now that Research Design funds have expired.

WHAT DID WE DISCUSS & WHAT HAS HAPPENED AS A RESULT OF THE MEETINGS? At our first session (Nov 2017) we spent time building rapport and explaining the aims and nature of the group. We discussed 2 qualitative projects being undertaken by medical students which involved researching 'Patient perception of pre-diabetes' and 'Access to treatment of respiratory disease for patients who also have a serious mental illness'. The students fed back to academic supervisors at The Academic Unit of Primary Medical Care at The University of Sheffield and incorporated the Deep End Panel opinions into the development of their topic guides for interviews.

We went on at the next meeting (Dec 2017) to welcome an academic urology surgeon and nursing academic to discuss their project ideas on screening for bladder cancer in deprived areas and developing a training package for nurses about domestic violence respectively. The panel's involvement has been an important part of the Urology teams application for a grant application to Yorkshire Cancer Research in June 2018 (£3.4 million).

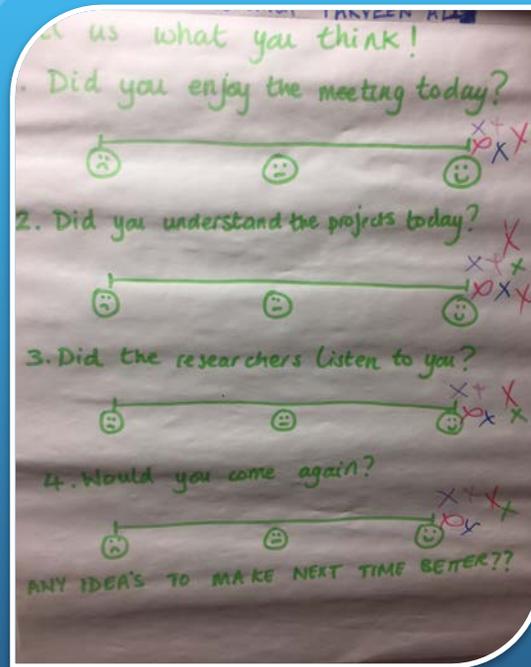
Dr Liz Such from the School of Health and Related Research presented her ideas for a project exploring the care of migrant patients in primary care in January 2018. We discussed how the panel felt about researchers observing new patient checks. The group reached a consensus that observational research was "imperative to the advancement and improvement [of patient care]; as well as standardisation of the health care of people arriving from overseas". This will be important when applying for research funding in the future to explore this aspect of health care.

In February 2018 we had a midpoint evaluation and teambuilding meeting. Now we were a stable group we learnt a bit more about each other by using the date on the sides of the

pound coins I had distributed as travel reimbursement. We used the year of issue of the pound coins as a prompt for us to share something of significance for us personally about that year. We had a fascinating discussion and I think this really cemented our trust in each other. We were then in a coherent position to run our workshop at the Regional Society of Academic Primary Care Conference in March 2018 where we discussed how to recruit to PPI in more deprived areas.

EVALUATION: We had our most recent Deep End Patient Panel Meeting in April 2018; although patients have attended professionals research cluster and educational meetings with us since then. 3 members of the undergraduate medical teaching team also joined us to discuss their ideas for health inequalities teaching and medical education research projects. We evaluated the panel so far and overall the feedback was very positive: as proved by the stability and good attendance at meetings. We did not use the standard RDS feedback form as the panel found them overwhelming so we used flipchart and group discussion instead. After every meeting I left the room and the Panel fed back on a scale as seen in the picture. At the final session the panel reported that they liked the group setting as they felt this less pressured than an interview style approach. They felt they had been actively listened too and that I was a 'good, trained facilitator' and enjoyed feeling they had positively contributed to something useful. People had felt nervous before the first session but now reported that they look forward to the meetings. The group had enjoyed giving feedback to academics but also valued some unintended consequences of the group as described below.

UNINTENDED CONSEQUENCES: I had not anticipated the positive 'sense of belonging' we all enjoyed from the panel meetings. We had become a friendly community. Everyone wanted to continue to come to the group and said it would only be work or illness that would stop them. Outside of the meetings the panel discussed healthy recipe's and our practice walking group (prompted by the pre-diabetes discussion), job interviews and also 2 of the panel are now helping with the medical schools communication skills training for students. We have had lively discussions about controversial issues at times but the panel is always respectful and it feels a very supportive collaborative environment.

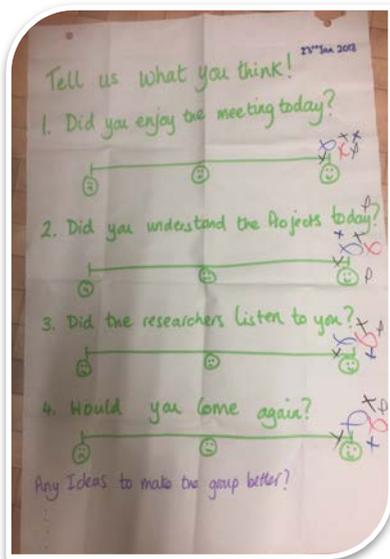


Panel Feedback December 2017 Meeting.
We discussed Research Projects about Bladder Cancer Screening & Domestic violence training.

CHALLENGES: Initial recruitment was challenging unless our practice staff personally invited patients. We did not manage to recruit through local community groups sadly. With no administrative support it was challenging and time consuming to access the cash advance and shopping vouchers through university systems and organize meetings. Patients were reluctant to take vouchers/travel money. Logging voucher numbers and travel receipts with signatures was disruptive to my welcome to meetings and time consuming. Understandably patients want information about meetings in different formats, but this was challenging without admin support.

THINGS WE WOULD HAVE DONE DIFFERENTLY: The panel fed back that they would like to hear more about researchers and their projects progress. I think I could have explained more effectively about how long research takes and that I am still in contact with all the presenters and that eventually we will have results and dissemination to consider. At times I struggled to contact all the patients through different media to organize meetings. I think some administrative support would really enhance this and allow me to send through prior notice of the agenda. I now understand the university system for cash and advance and will order vouchers online as this is much easier. I have joined a special interest group for researchers interested in PPI and attended a first meeting of the group at the National SAPC conference in London (July 2018). I would like to seek advice and tips from this group on taking this panel and other Deep End PPI work forward.

Plans for 2018/19



FUNDING

Sheffield CCG Health Inequalities Steering Group have kindly offered to continue supporting the panel through funding patient travel and vouchers. I will forward them a plan for this alongside this report in July 2018.

COLLABORATIVE WORKING

I will build on links with The Society of Academic Primary Care Special interest group and also raise awareness of the group with the Clinical Research Office at the Royal Hallamshire Hospital and the Public Engagement Team at the University of Sheffield. I will approach local community groups again to enquire about setting up some Panel discussions in community venues outside of the Surgery.



FOLLOW UP FROM PREVIOUS WORK PRESENTED, DISSEMINATION & WORKING WITH EDUCATION

I will contact all previous presenters to the panel to find out progress with their projects to feed back to the panel. I will plan for a feedback meeting in Autumn 2018.



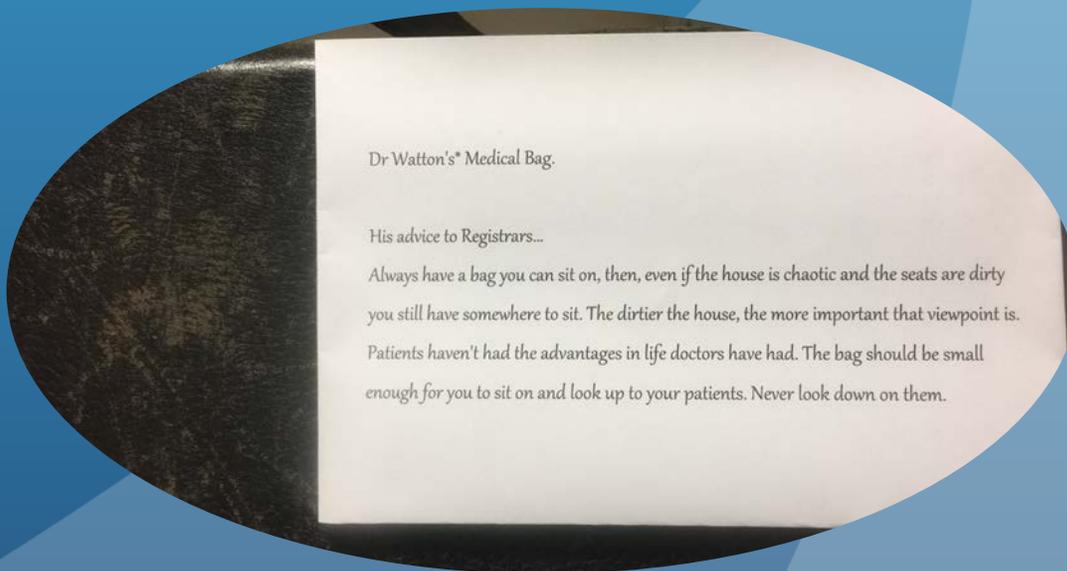
LESSONS LEARNT

Building on the success of the Deep End Sheffield panel I would like to set up another patient group in a contrasting part of the city with patients to comment on my own future research project to look at what GPs and primary care teams can do to reduce inequity.

APPENDIX

BREAK DOWN OF EXPENSES OF THE PANEL

PPI Group expenses			
Cash advanced from University			£100.00
Received Expenses	refreshments for 13.11.17		£44.83
	Refreshments for 27.2.18		£4.21
	Total Expenses for refreshments		£49.04
	mileage allowance for attendees		
		13.11.17 at Deep End	£4.00
		27.11.17	£1.00
		18.12.17	£8.00
		23.1.18	£12.50
		27.2.18	£10.50
		13.3.18	£14.50
	Total Travel Expenses for participants		£50.50
Unreceipted Expenses			£0.00
Cash retained			96p & -50p=46p
Love to shop vouchers	2.11.18		£300.00
	17.4.18		£100



*Dr Watton was a GP partner and Trainer at The Whitehouse Surgery on the Manor Estate in Sheffield for 29 years. He generously shared his wisdom and experience with colleagues and juniors and left some of his famous 'Wattonism's' in the library at his practice on retirement. I was drafting this report and glanced up at this quote on his battered Doctors bag while taking a break from writing.

It seemed very appropriate to underline the importance of always valuing patient's opinions. This was reinforced by this work, as I found the patient panel raised exactly the same challenges, themes and questions as the professionals when reviewing researchers ideas. The professionals may have used a different lexicon, but the essence of the concepts they raised very much mirrored the patient panel.