

Comisiwn Bevan Commission

Patient driven solutions to common problems:

Education Programmes for Patients (EPP)

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EXECUTIVE SUMMARY

The Bevan Commission has recognised the unsustainability of the current healthcare system in Wales which predominantly treats ill-health at the expense of promoting health and wellbeing. This has recently been reinforced through its Prudent Social Model of Health series (Bevan Commission 2017,2018). This sets out how health is everyone's responsibility, not just the NHS. It cannot be based on fixing people when they become ill in the traditional way, but must be one which is sustainable and engages people and their ideas, making them jointly responsible to produce their own health and wellbeing.

Education Programmes for Patients (EPP) is a successful and widespread programme of patient empowerment and self-efficacy in Wales. It provides a prudent method consistent with the principles of value based healthcare. Its problem solving exercise provides a valuable way to access the views and experiences of patients and their carers. This report describes the outputs from 93 EPP courses with 797 participants setting out over 1400 issues and challenges that they face on a regular basis.

The outcomes of this work provide a rich and unique source of the wide-ranging challenges that people with chronic disease in Wales can face. The solutions proposed by the participants were broadly grouped around either how to change the system or how patients could be better prepared to interact with it. There also appeared to be an overestimation of the expectations, particularly regarding the role of GPs.

While many patients would often be better suited to meeting with a specialist best placed to meet their needs, e.g. pharmacist, chronic condition nurse, Occupational Therapist, physiotherapist or social worker, it appears that many people are unaware of this and the avenues to access support. This would suggest that there is a clear need for greater understanding and awareness of how the system operates, and how patients might be empowered to help manage their care and their expectations.

This report sets out the following key recommendations:

- 1. Emphasise the importance of the patient as co-creators of their own health and wellbeing with patients and professionals.**
- 2. Enable patients to become custodians of their own health information, through cloud-based patient records and other tools that can be amended by the patient.**
- 3. Increase health literacy and knowledge of how the system works to help make shared decisions and manage expectations.**
- 4. Undertake further research for future EPP courses, to look at differences driven by geography and deprivation.**

BACKGROUND TO THE REPORT - JULES'S STORY

My story begins in 2012 whilst suffering effects of depression post-cancer, along with a number of other health conditions. I reluctantly went on an Education Programme for Patients (EPP) course in Chronic Disease Self-Management in Pontypool, Torfaen. I had no expectations from this course as I already felt I was an 'expert' in keeping myself alive and was also a full time carer.

What I found when I started the course was that I was not alone. Every other person in that room including the tutors were also suffering long term health conditions like me. The support that everyone gave to each other was incredible, the sharing of each others experiences although suffering different conditions were so similar it was striking.

We undertook problem solving exercises that helped participants to start to work out problems for themselves and also helping others by giving their ideas to these common problems. This produced a wide range of solutions, generated by people like me about issues that we and many others routinely faced, wouldn't someone be interested in hearing about these?

It seemed a crazy waste of such valuable information to me and I became determined to make sure that it could be seen and heard by people able to do something about it. So often there seems to be a constant 'put down' of the NHS System in media but so often the voice of the people actually using the system was unheard.

Soon I became employed as a coordinator for EPP and I was often being asked to speak on behalf of patients by telling my story. This then led to me applying to become a Bevan Advocate and with the support of the Bevan Commission I have had the opportunity to bring together the experiences of over 750 EPP participants in Wales.

This report with support from my colleagues from the Bevan Commission, Public health Wales and Swansea University sets out some of the most commonly reported issues and more importantly practical solutions, identified by people who use the system as patients and carers. The NHS cannot continue to keep fixing people, it must help people to help themselves and each other but it also must listen to people about what is important to them. I hope you find the report and its findings useful and ask you that you all keep listening and involving people in what you do.

-Jules Horton



ABOUT THE EPP PROGRAMME

For over 10 years, self-management courses have been provided through Education Programmes for Patients (EPP). EPP courses support individuals with a range of chronic conditions to develop the skills and confidence to better manage their own care and make better use of health services, whilst also encouraging them to work in partnership with health and social care professionals. The majority of EPP participants are referred to the course by healthcare professionals. They either have a long-term chronic health condition or are a carer for someone with a chronic health condition.

The EPP courses can be tailored to different conditions/syndromes but follow the same general structure over a period of six weeks. The volunteer tutors, who have previously attended an EPP course themselves, take participants through a journey to identify self-management tools to assist them with living with their symptoms. Effective self-management is important for preventing secondary problems such as depression and anxiety. Central to the courses is working with individuals to find the best way to manage their condition through training and peer support.

As part of the session, participants learn how to make better-informed decisions and problem solve their everyday issues. Courses also provide opportunities for building skills to coordinate all the things needed for managing personal health and well-being as well as helping individuals to stay active.

Participants are also helped to develop their communication skills to empower them in to take greater responsibility for their health in partnership with healthcare professionals.

Any person living with a chronic condition can access the knowledge, skills and motivation they need to feel more confident to better manage their personal health and well-being, with the support of easily accessible, high quality information and highly skilled professionals and lay individuals.

BEVAN COMMISSION

The concept behind Prudent Healthcare (Bevan Commission, 2015) came at a time when nationally and internationally a number of different ideas and ways of delivering future health and care services were being developed. Prudent Healthcare arose in response to the challenges of austerity and the need for a more robust, meaningful and workable way to tackle the current demands on the NHS and address the future burdens that increasingly frustrate the sustainability of the NHS.

The Bevan Commission recognised the many pressing drivers for change and the need to focus much more on seeking to ensure fairness, equity and the pursuit of quality, alongside the effective use of all skills and resources. The philosophy and principles of Prudent Healthcare and the underpinning prudent model strongly advocates a new way of thinking and working based upon the four prudent principles.

A prudent approach sets out a different tone and ethos: a co-operative approach based upon joint responsibility and ownership, engagement and partnerships between patients, professionals and the public. A prudent health and care system is one in which we all share responsibility for maintaining health and wellbeing of ourselves and people in our communities. It demands high quality, effective and efficient services which meets the needs of people, as and when needed. Implicit in a prudent approach to health is the need to redraw the relationship between the citizen and the state.

Empowering people and communities to take greater responsibility for their own health and wellbeing and building resilient skills into our future generations requires a move away from the more traditional 'passive acceptance' and top down 'paternalistic' approach, to one of 'proactive participation'. Within this, the rights and responsibilities of individuals are a key consideration.

The Bevan Commission (2016) expanded upon its thinking on this in 'Redrawing the Relationship between the Citizen and the State'. In this, it recognised the need to engage more effectively with the public, patients and carers on a more equal basis by identifying and owning the problems and in helping to find better solutions together. It described the need to redistribute the balance of power, sharing and managing the risk to enable the changes that need to happen.

POLICY CONTEXT IN WALES

There is a long-standing ambition by Welsh Ministers of creating world-class health and social services in Wales: 'services best suited to Wales but comparable with the best anywhere' (Welsh Government, 2011). To achieve this against the backdrop of increasing demand and austerity will require a very different approach and culture than is evident to date. With this in mind, Welsh Government adopted the Bevan Commission's prudent healthcare approach as its underpinning principles and which was reinforced recently through the both the Parliamentary Review into Health and Social Care in Wales and the subsequent 'A Healthier Wales: our Plan for Health and Social Care'.

The Parliamentary Review into Health and Social care in Wales (2018) called for 'revolution not evolution' and a new system of care where change is significantly accelerated 'unless faster, more widespread progress can be unlocked, access to and the quality of services will decline in the face of the predictable pressures'.

Consistent with the Bevan Commission's perspective, the Review recognised the assets and power of service users and communities in driving change, along with the ability of the workforce to test and learn what works and to accelerate change and innovation. The Wellbeing of Future Generations Act (Welsh Government, 2015) also recognises that to give future generations a good quality of life we must all work together now to tackle the challenges to improve the social, economic, environmental and cultural wellbeing of Wales.

In response to the Parliamentary Review, Welsh Government (2018) set out its vision of a whole system approach to health and social care in its plan for health and social care- 'A Healthier Future'. Within the plan, there was a recurring emphasis on engagement with both the public and healthcare staff. Clear actions were outlined around an 'offer of involvement' which included the need for continuous engagement and an ongoing conversation with the Welsh population to ensure everyone has a voice.

RATIONALE

Innovation is expected to play a central role in the transformation of health and care services in Wales and user engagement is a critical component of successful innovation processes (Rothwell, 1992). As the way health and care services are delivered move towards more patient centric, personalised approaches, the integration of patient perspectives will become increasingly important in designing effective, evidence based interventions.

Given this recent Welsh Government policy impetus and the Bevan Commission's commitment to embed a co-productive approach in health and social care, we explored the potential of outputs of the EPP programme to act as a unique mechanism for the patients and the public to both highlight key issues and propose solutions.

METHOD

THE PROBLEM SOLVING EXERCISE

Towards the end of the EPP programme, a specific exercise is undertaken to identify challenges with the healthcare system and healthcare professionals through the eyes of the patients. This problem-solving exercise produces a rich source of patient-driven issues and solutions experienced within the healthcare system first hand.

The course tutor takes the participants through the problem-solving exercise. They are asked to individually list the greatest issues and challenges that they face as a patient. Then as a group, the participants decide on the one key issue or challenge that they feel is the most important and that could be solved. Together, they then suggest a range of possible solutions to this one issue or challenge. From the problem-solving session in each EPP course there were three key outputs:

OUTPUT 1

What is the biggest issue or challenge that you face?

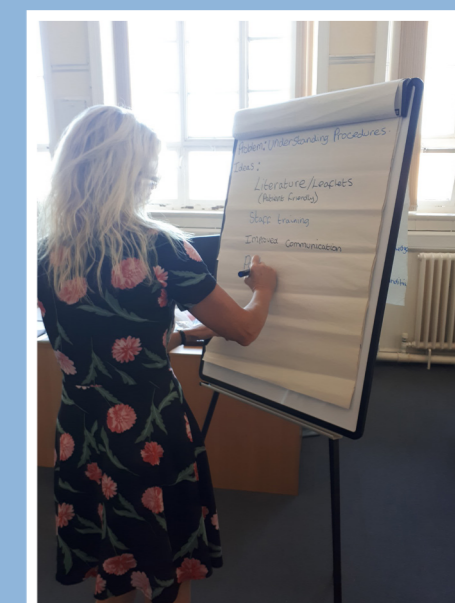
OUTPUT 2

What is the one key issue or challenge that could be solved?

OUTPUT 3

What solutions are there to this one issue or challenge?

Prior to this project, EPP Course Tutors would write these outputs on flipchart paper, which was then disposed of at the end of the course. For this project, tutors took photos of all Flipcharts generated in the problem-solving session. These were then emailed to the project team for transcription.



ANALYSIS OF THE DATA

All images were transcribed and course details, health board, number of attendees and course tutor were recorded. To protect course participants, no identifiable data was used in highlighting issues or when proposing solutions. A qualitative research design was adopted consisting of thematic analysis of transcribed responses to identify key emergent themes which are then reported.

Thematic data analysis was initially progressed in an inductive fashion, starting with identifying themes and categories suggested by participants themselves. An iterative process of analysis was then followed by individual members of the project team individually analysing data from separate events, before coming together to agree emerging themes.

This method of analysis enabled the progressive understanding of the responses gathered to interact with the project teams emergent thoughts, with the overall aim of understanding the key issues that matter to participants who have undertaken the EPP programme.

The aim will not be for the project team to arrive at the exact same themes but for similar themes to merge, meaning the data were carefully analysed to provide a reduced, yet accurate representation of the EPP participants' views. This process corresponds with approaches to establish rigour in qualitative research, in particular establishing credibility, which represents means of conferring value and believability to qualitative findings (Jones et al 2015).

What Problems do you have with the Health care system?	What Problems do you have with your Health care Team?
Getting an Appointment	Jargon
Waiting times	Seeing same GP twice
Automated check ins	Poor Admin (e.g. letters for)
Appointment Length	by Passing Receptionists
Waiting for beds	Privacy at desk
Continuity	Understanding Strong accents
Getting test results	Too much/Too little information
Automated phones	Not feeling I am believed
Parking	Receptionists Lack of knowledge (medical)
Poor Discharge Service	Not being Looked at
Privacy	Being treated as the condition not the person
Understanding * Procedure	

RESULTS

Between April 2017 and August 2018, over 93 EPP chronic management courses were delivered. In total 797 individuals attended these courses and the participants identified and generated almost 1400 issues and challenges that they faced.

OUTCOME 1

What is the biggest issue or challenge that you face?

Many of the issues and challenges reported related to participant experience of primary care especially within the GP surgery environment. The key themes are below, with examples of the challenges within the theme.

THEME 1: Communication

- Communication both with health care professionals but also within the system itself.
- Lack of control and ownership, not understanding staff, jargon, feeling rushed, not able to ask questions.
- Continuity of care and consistency, lack of notes and clinical information, lack of ownership by staff.
- Lack of Privacy - Talking to staff in front of other people.

THEME 2: Infrastructure

- Car parking
- Pharmacies not close to GP
- Referrals to hospitals far away
- Hospital transport services
- Too much Technology (interaction / tech in system) e.g. automated sign-in systems in GP surgeries

THEME 3: Access to Services

- Rurality
- Distance to access health and care appointments and specialist services
- Difficulty accessing specific services e.g. Dental appointments
- Appointments – (lack of) access, (too long) waiting times, (lack of) consistency of healthcare staff
- Discharge Care – fragmented care landscape, with patients falling between cracks

The key emergent themes for each of the three outcomes are presented below.

OUTCOME 2

What is the one key issue or challenge that could be solved?

THEME 1: Communication

- Communication with and within the healthcare system was a key recurrent theme that could be seen across many of the solvable issues identified.

THEME 2: Interaction with the system

- Getting any form of appointment – interaction with the system

THEME 3: Personal ownership of care

- Lack of personal ownership for care (driven by a medical model of care)

THEME 4: Lack of joined up care

- Test results going missing/different healthcare professionals delivering care

OUTCOME 3

What solutions are there to these problems?

THEME 1: Greater clarity, knowledge and understanding of the health system to manage patient expectations

- Improving health literacy, variety of professional roles, timelines, not being forgotten

THEME 2: Patients proactively preparing for appointment and meetings with healthcare staff

- Holding notes and personal information, awareness of condition, managed expectations e.g. 10 minutes with GP

THEME 3: Changing culture to improve interaction with front line staff.

- Expectations, reduced jargon, privacy and confidentiality

KEY FINDINGS

There is a clear lack of communication both with, and within, the health and care system, between health professionals and with patients and this is often a key factor affecting patients and their carers. It fragments relationships between those delivering and those receiving care and also affects ongoing continuity and consistency of care. Patients are referred to as experts of their own condition (Stacy & Spencer, 1999), often possessing high levels of knowledge, offering a multi-dimensional perspective on challenges facing healthcare systems resulting from a vast array of interactions with both tangible and intangible aspects of service delivery.

It often appears that the current design of the health and care system is driven not by the needs of the patient and the wider population but by the system itself. Control and therefore power is mostly associated with the healthcare staff and the system and not the patient. The solutions proposed by EPP participants were grouped around either on how to change the system or how patients could be better prepared to interact with it. There also appeared to be an overestimation of expectations particularly with regards to GPs.

While many patients would often be better suited to meeting with a specialist who is best placed to meet their needs, e.g. pharmacist, chronic condition nurse, Occupational Therapist, physiotherapist or social worker, it appears that many people are unaware of these avenues to access support. This would suggest that there is a clear need for greater understanding and awareness of how the system operates, to empower patients and help manage expectations.


Interestingly, while many of the solutions that were proposed were often simple, they addressed issues that were complex, often cultural in nature and appeared deeply embedded.

CONCLUSION

The Bevan Commission believes that health is everyone's responsibility not just the NHS. The Welsh Government's long term plan 'A Healthier Wales' (Welsh Government, 2018) reinforced this recognising that services are only one element of supporting people to have better health and wellbeing throughout their whole lives. It will be a 'wellness' system, which aims to support and anticipate health needs, to prevent illness, and to reduce the impact of poor health. This is a considerable challenge and will require strong collective leadership and commitment by all those providing services as well as those using services, to make a real difference and achieve a more prudent, seamless approach to health across Wales.

The EPP programme is a successful pan-Wales initiative that supports carers and patients with long-term conditions to take control of their own health and is therefore a useful tool in achieving both a more prudent approach to health and care and the future goals of Welsh Government. This report has identified that within the EPP programme there is a rich source of information about key issues and challenges faced by participants. To date this information has not been available to inform those leading and delivering health and care services.

Patients and their carers can provide a key part of the puzzle to developing effective improvements in service delivery. However despite this, users are commonly report to be ignored or used in a tokenistic manner (Cotterell et al., 2011). Such actions present both a persuasive and moral argument for the inclusion of user perspectives in decisions that could ultimately impact the health status of the individual (Boote et al, 2015).

For Recommendations see overleaf. 

RECOMMENDATIONS

1. Emphasize the importance of the patient as co-creators of their own health and wellbeing.
2. Make patients custodians of their own health information, using cloud based patient record that can be amended by the patient.
3. Increase health literacy, increase knowledge of how the system works to manage expectations.
4. Build in a funded evaluation programme for future EPP, to look at differences driven by geographical and deprivations.

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