“Why and how to ensure patient involvement ”

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Why (not!)

In the 21st century – there is the movement away from professionals controlling care to shared responsibility for improving health and care between patients, the public and both clinicians who provide care and support and others working in public services

Patient & public participation in commissioning health and care (NHS England, 2017)

The Patient Act, Sweden (2014:821)

People With Lived Experience at the Centre of Canadian Stroke Best Practice Recommendations: A Model for Guideline Developers (Journal of Patient Experience, 1-6 ª The Author(s) 2020)

Challenges faced in patient involvement in the implementation of a national stroke plan

Creating the environment to allow people to make choices about their health

1. Dominance of other conditions
2. Political/health system structure
3. Cultural challenge
   - Health systems
   - Political system
4. Capacity, expertise, resource
   - The pandemic
   - Involving the right people
   - Patient, SSO, neurologist, therapist time

Principles of participation

- Reach out to people rather than expecting them to come to you
- Seek participation from people who experience health inequalities
- Promote equality & diversity & encourage & respect different beliefs and opinions
- Value people’s lived experience & the strengths and talents that people bring to the table
- Provide clear and easy to understand information
- Take time to plan & budget for participation
- Be open, honest & transparent in the way you work
- Invest in partnerships, have an ongoing dialogue & avoid tokenism
- Review experience (positive and negative) & learn from it
- Recognise, record & celebrate people’s contributions
- Set up actions that would be measurable. This is the only way to evidence the improvement

Sources of information on patient experience

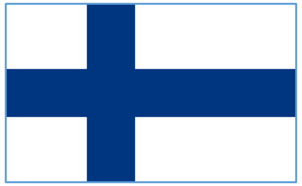
- Surveys – local, national, European
- Research reports
- Intelligence from health & community services, the voluntary & local government
- Staff feedback including their own views, any ‘whistleblowing’ concerns and intelligence gained interactions with patients & the public
- Patient feedback – including complaints
- Previous public involvement exercise
- Social media

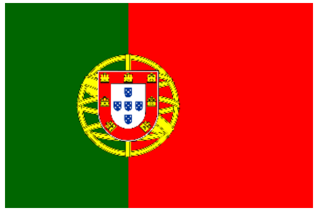
“Talk about money. Human suffering is important factor, but when talking to decision makers on national level, keep in mind they are interested in costs and savings, people´s ability to work and stay at work (taxpayers) and the scale of the problem. How many of us is likely to get a stroke in our lifetime and how many stroke survivors we have, seems sometimes to come as a surprise. And don’t forget to mention that stroke is not just problem of elderly: more and more of the survivors are of working-age”.

Finally – hope for the future

There are few experiences about patients and professionals working together.
The creation of local SAPE Committees including both profiles would be a first step in this direction.

The overall situation is, if not good yet, at least promising.





There's a lack of awareness and life after stroke isn't a topic for politicians... But stroke survivors never quit and Portugal AVC will keep on working 💪💪💪

In these social, political and pandemic situation it is hard to succeed, but we are not giving up ! We will keep our efforts and wait for our opportunity to make further steps for developing and implementing a National stroke strategy!

We must keep on contacting the healthcare, politicians and decision makers an offer our services and experiences as a resource from the patient point of view. In Sweden it is now a habit and culture to invite our organisation in this kind of work. It is a great opportunity to influence early in the processes.

Thank you for listening - arlene.wilkie@safestroke.eu