

Draft record/basis for mini-report

Greek Presidency Conference: 2014 eHealth Forum, Athens

Wednesday May 14th: 14.00-16.00

EIP parallel session: expert forum on community empowerment and technology: implementing the new paradigm

(Bullet points abstracted from a recording of the two hour session of presentations and discussion)

1. In the field of patient and community empowerment, how can we support the work of the EIP to make a difference?
2. Although empowerment was identified as a horizontal, cross-cutting issue for the EIP we're not convinced that the mechanism has been effectively established yet.
3. In convening this meeting we had in mind as an outcome of the session a mini-report to the Commission: that summarises two elements -what we think about this issue and what we think is needed.
4. One argument raised is that community empowerment is very much about mobilising resources and ownership, while patient empowerment is individualised, they're different processes. In such a view it is community empowerment that can lead to our goal of increased life years. However others are not so sure that there's such a clear distinction; as some of the presentations may show.
5. There are a lot of initiatives that have been launched and they don't necessarily connect up as they should.

What followed on the day were 8 presentations. A précis of the main points raised in each presentation is attached as Appendix 1

The discussion (version of fuller transcript is available):

(What the group thought)

6. Talking about good practices...are we in a parallel universe to the rest of the world? There are always product champions, there's no lack of expertise or dedication amongst this group, but is there any real change, any worthwhile influence we can bring to bear on the majority?

For example how do we extrapolate the good practices that have been collected especially to the vulnerable, the poor and the deprived members of society and in complex settings?

7. A common theme is identified in the words of this participant: *'If you're describing potential service models; this is about knowledge transfer and that's happening in the EIP to a degree, e.g. we're working with colleagues in Denmark on particular service models to look at transferability of ideas – we don't need a dedicated platform for knowledge transfer but we do probably need a different kind of vehicle to facilitate the exchange.'*

8. Other points raised are:

- *How do we open this to the wider society, in our own country? Might we think about some sort of awareness campaign?*
- *ICT is about more efficient sharing of experiences, but for me it's also about trusting each other, sharing learning points, sharing our problems. It's a mechanism which could be facilitated more, making contact with members of other networks outside of the EIP*
- *We have all been in hundreds of meetings of this kind and we can have a very intellectually stimulating discussion and then nothing happens. The reality is that there are very few of us who will stand up and be counted to move forward and make effective change. To do that you need allies, not only in your organisation but outside and it's at events like this that you have the possibility of forming networks to give you support to produce some of the evidence from elsewhere to counter the doubters who say 'it's dangerous' or 'it'll never work'.*
- *If we agree about the evidence that's needed and about transferability we need to be as pragmatic as possible and have both a long-term perspective and also a consumer perspective; that is we need to organise more groups of consumers to learn from their experiences and what they think of this work.*
- *What makes a difference here? It's not about better use of technology data, it's about the ethos, the values and the beliefs of the people applying that technology and what goes with it. So getting this massive paradigm shift, it's not just about saying, these are the examples of innovation and good practice but how can we*

create the environment for that to happen? It involves a very different kind of learning and it involves a fundamental shift in how we support people to acquire it.

- *How can we share this with more people? We could take a challenge to people doing this kind of work and involved in these kind of networks and say well you were in this discussion now go and find someone who isn't involved in the work of empowerment and share you knowledge with them, and the other challenge is to find other people who are involved in the subject and see what you can learn from them. This way we can share our knowledge more broadly than can happen in the EIP.*
- *It's really important that we pick up all of these points and we make sure that the Commission, both SANCO and CONNECT get the message from us of bringing the parallel universes together. We should say to them 'here's the things that we would like you to do, very specific, can you do them within the timelines'. We think we would be pushing at an open door but its incumbent on us, with so many different viewpoints and opinions in this room, to come to some conclusions so that we then pass them on to the Commission. But what else are we going to do?*
- *We need to take things forward. 'One possibility is to abstract from our group here a couple of success stories, real success stories: then the challenge is how do we, and to whom, do we transfer them to. Remember you have another layer of network, we have the reference sites, they are all trying to do certain things, there's the ecosystems run from the Alliance; so we do have a lot of the mechanisms and we don't need to keep creating more, but we could utilise them better...I still worry that the EIP, the ecosystems and the reference sites are not actually themselves properly joined up.'*
- *How to make this more inclusive? To return to the theme of experiential learning – it would be very interesting if the EIP provided the opportunity for training: how can professionals in Crete see how things are being developed in Scotland, for an opportunity to talk together, but not to make presentations but to participate in workshops as observers and find out how do we train them, how do we talk to the community, these kinds of things? To*

give this opportunity to bring people from different levels of literacy so that they can become then the champions to their own place so that they can see who they should talk to, how do they overcome the non-communication, the power issues and go towards synergies

- We need to work more on our communications strategy and we have to be more in a conversation and that's really another way of communicating for experiential learning and we have to facilitate the kind of infrastructure that supports that*
- We've been talking about collaborating and seeing how we can share our experience. There's a lot of content that's around in the field which is good, great work being done but the process of transferability is of interest to all of us and needs more attention. So rather than providing more content in interventions and best practices we have to step a little bit higher into the process of transferability and sharing experiences and the context is important, so we need the knowledge about the context and how content is affected by context and the other thing is marketing – it's an important issue – so, process, context and marketing.*
- One final thing; to put out a response to the CSA when someone's appointed to the post. It's great that the Commission has enabled that (in the H2020 call) but their role on establishing horizontal action groups is desperately needed*

9. Summary of themes from the above bullet points:

a) the whole concept of patient and community empowerment is complex and depends very much on context. Nevertheless good work is currently going on within the Commission in clarifying definitions and promoting this area for policy development, not just as an aspect of quality improvement in health but as an essential component of the redesign of healthcare delivery systems.

b) effective knowledge transfer is identified as a key issue for the success of scaling up from individual examples of excellent practice, within the scope of the EIP but elsewhere also. It is finally being realised that a lack of understanding of the mechanisms underlying successful knowledge transfer has held back the evolution of quality improvement.

c) extrapolation of good practice in 'difficult' i.e. less than ideal conditions such as where there is significant health inequality is a specific problem.

d) there needs to be more awareness building, to supplement the Commission's current communication strategy, for this important work flow. There needs to be greater inclusiveness, especially of consumers of health services. (Overlapping with this point....)

e) inclusiveness could be explored through training, that is, sharing knowledge through experiential learning (including placements/visits?)

f) the current EIP networks need to be linked to other existing networks, to facilitate flow of information about the activities particularly via personal exchange of knowledge and experience (Overlapping.....)

g) there need to be better linkages within the EIP, between the Action areas (especially on horizontal themes such as patient empowerment), between the reference sites, with the ECHA ecosystems etc. and better communication between partners across the EIP (even though communication within action groups may be quite good) may be a corollary of the above point about connectedness.

h) these observations need to be fed back to SANCO and CONNECT and a discussion ensue about their potential value (EU added value) or applicability to current activities.

**Possible actions that might arise as a result of the above feedback:
(what we think is needed)**

This section needs to be thought about. The Commission could say about the above points a) they're intending to do some of this anyway and b) some of it isn't really practicable. There are inevitably also vested interests who might feel that our initiative, for what it is worth, might potentially interfere with their activities.

Possible actions are:

1. An ongoing network of interested parties over and above what is envisaged by the strategic plan for the EIP, using the Athens group as a core for further growth (possibly connected with the EHFF-facilitated EMPATHIE network and the Utrecht based eUcepS project).

2. A patient empowerment working group that is developed by the coordinators of the action areas (something to be explored and developed by B3 activists linking with like-minded persons from the other Action groups).

3. Patient empowerment becoming a cross-cutting topic of interest for promotion by the coordinators of the network of reference sites (an idea to be put possibly to the next meeting of the Reference Sites Collaborating network).

4. Discussion with SANCO and CONNECT staff regarding these options, which are not mutually exclusive.

Appendix 1: précis of presentations. Copies of PowerPoint slides available either separately or as a combined presentation.

1. Nick Guldemon: *defining the paradigm shift*. The shift is from the medical curative model to a social (interconnected) health perspective. Integrated care is a key component bringing together the elements of the activated community and proactive, supportive health systems to produce improved outcomes.

2. Jim Phillips: *the patient's perspective*. As a patient with a chronic condition, it's a journey from a passive position, investing all our faith in the professionals' know-how via getting to know our own health to an activated role where the process of our mapping options and choices can take place. The umbrella of factors which facilitate this movement are communication skills, health literacy, personal health information, self-care support, decision aids and being connected. My wishes involve a cluster of factors (e.g. building on my skills, being able to make lifestyles choices) but the core goal is gaining confidence. The quality of communication between professionals and the patient is crucial to the patient feeling undermined or supported. It is essential that support comes from professionals that recognised the importance of my (mostly non-clinical) needs, rather than trying to impose their ideas of what I need. Finally, there are mechanisms potentially available that allow me to achieve a key objective: I want to own and manage my own data and to choose who I share it with.

3. George Crooks: *the NHS24 Scotland health professional view*. With the help of new technologies we can move from supported self-management to co-production – delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Community engagement benefits from the utilisation and bringing together of 'invisible' resources: untapped individual creativity, skills and experience; the willingness of community to 'give back' and use of technology. Our vision is that if health, care and well-being is person focussed, we increase choice, control, connectedness, collaborations, contributions and enhance communities. Our mistakes in the past have in part arisen from service redesign based on the service's needs rather than those of the customers. More sustainable health systems for the future are not primarily predicated on new technology or more money, but on thinking differently.

4. David Somekh: *an NGO perspective* (www.ehff.eu). If one compares models from ten years ago, the overview of key elements of quality in healthcare and the model of the structures of ICT that can connect up the healthcare system, for both modalities today, the elements of the structures are still valid: both quality and ICT experts recognise that it is the process of change, the nature of the long journey, which has been clarified over the time. It involves the necessity for transformational change in order for change to be sustained. Good practice examples aren't enough. We need to explore new ways of working together and learning together.

5. Floor Scheepers: *integrated psychiatric care* (www.psynet.nl). The PsyNet platform was formed via collaboration between UMC and two small ITC providers, pazio.nl and topicus.nl. The characteristics and potential of the platform are: patient centred, coordinated by patient if possible, communication platform for all participants (potentially family member/mediator also), overview of all activities (including diet, accommodation, and occupation), possibility of personal health record; single sign-on with different ICT medical files. It is an example of the principles set out in points 7 and 8, above, put into practice.

6. Gianna Tsakou: *perspective of a software company; ICT as enabler*. Facilitators for community empowerment via ICT are well known; barriers include diverse regulatory frameworks across MS which introduce complexity in adopting enabling ICT and creating/identifying the right content for e-Health services which can be time/resource intensive. Enablers of success: addressing recognised problems rather than creating them to sell products, well targeted solutions, attractive HMI for individuals, blending 'pure health' with 'general well-being' services, non-intrusive solutions and more co-design and collaboration.

7. Donna Henderson: *ecosystem example; 'Living it Up (LiU)'*. Led by NHS 24 Scotland, www.livingitup.org.uk will co-design sustainable and innovative improvements and choices in health, care and well-being for 55,000 people by 2015 using familiar technologies. It is an example of putting the principles outlined in point 9, above, into practice. The iterative design process for the project is described (slide 3) and finally the functional outputs; engaging older people under the headings: Shine (what are you good at?); Flourish (what keeps you well?); Discover (what's available to you locally?) and Connect (who would you like to talk to?).

8. David Horsfield: *ecosystem example; 'More Independent (Mi)'*. Liverpool Clinical Commissioning Group have developed a community-based user empowerment model that embodies the principles of inclusion, co-creation, awareness raising and confidence building with take-up of smart solutions by primary and secondary end users for self-care and independent living. It goes somewhere towards answering the issue raised in point 4, above. Innovative communication methods in the community include training 300 community volunteers across the city to talk to their peers about what services are available and in the creation of an open-plan 'smart house' as an exhibit in the City Museum. In regards to the important matter of necessary infrastructure, independent of healthcare provision (in other words, a more holistic approach) access to the internet is also an issue in the Liverpool community and via collaboration with other stakeholders 56 digital hubs have been set up to help people learn how to use the internet. User empowerment is a moving target and our final message is 'keep changing'

Appendix 2: Attendance list for circulation of materials.

Athens audience listing May 14th

(NG) Nick Guldemon N.A.Guldemon@umcutrecht.nl (co-chair)
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