

ELF Patient Organisation Networking Day:

Shane Fitch: Q&A follow up

From Janette:

Q: Language isn't just about English, Dutch, French etc but the complete translation needed between clinical and lay terms - e.g. shielding guidance for lung cancer stated 'radical radiotherapy' whereas many patients are on 'palliative radiotherapy' but as far as they were all concerned' this was radiotherapy so felt they should shield..... many who are told their lung cancer is terminal feel they'll die in the next week or so rather than realistic explanations about treatment possibilities and living with conditions including lung cancer for some time.... how can we encourage healthcare professionals to use clearer language whether in patient letters or in consultations to improve understanding? some reflective questioning at the consultation may reveal gaps in understanding so may be a starting point. What is your experience?

A: Hi Janette, I believe you need an intermediary who understands the clinical care aspect but also the patient concerns. These people need to produce content which helps guide patients and use suitable platforms where the patient can Q&A easily, keep their personal information, and responses in one secure digital location. When these files or progress report is accessed by the physician, they can have a different dialogue in their consultation.

This is why safe digital information harvesting "translation" and content delivery is so important. The digital environment really helps us much better to focus on these key issues and attend to them more efficiently when we use the right processes, locations for exchange and train the people involved in bridging between physician, specialist and patient.

From Janette

Q: In some online forums to which I belong, it is even people sharing their relative's clinical letter that they don't understand terms like gg opacities, nodules, etc or staging numbers so the GDPR rules/policy are out of the window already..... people share the info as they are trying to learn more especially as they're unable to accompany patients to their appointments so haven't heard the detail firsthand... are there any plans to offer more written info or online resources with patients/relatives since the pandemic?

A: Getting advice on general terms or meaning of clinical speak is not tabú, of course, it's more about where that is being done and if it is personal information or not. Plus the discussion period around these issues can be much longer and less fruitful in satisfying peoples' desire for accuracy in fbk environments. These go around in circles often, confused and halftruths or concepts keep alive false ideas about information.

Using environments which are safe and moderated by people with clinical knowledge and specific disease related knowledge can lead to a much quicker resolution for answers and clarity and eliminate the anxiety around the long trail to find answers.

People need to understand that in the trusted environments, they need to consent to sharing to begin the process and the relationship and this leads to a speedier resolution of unresolved issues or issues which appear to have no way forward.

From Catia:

Q: What is your opinion of doing interventions in schools and working on all these psychological and physical exercise issues when they are young and thus improve their quality of life as adults?

A: Hi Catia, I think working in schools on lung health & preventative care is essential. We have worked on asthma but the difficulty is the schools being able to logistically organize themselves to hold external events.

We have planned a pediatric mhealth study with youngsters and kids for the autumn, for poorly managed asthma. We will be including attractive av content including anatomy to help kids understand more about their lungs. Our coaches will offer psychosocial support and guide in suitable exercising as well as continued content where we detect specific issues or problems. We will also use social media to amplify important lifestyle changes with Ambassadors who are young people with diseases, overcoming their own issues and advancing in their dreams and ambitions, in spite of their health and other issues.
#InspiringKids.... @HappyAirCommunity

From Mark:

Q: What "device" is Shane talking about?

A: Hi Mark, I am not sure if we mean here the HappyAir platform which is accessible from any mobile device, tablet, PC etc and is adapted to any OS.

Within HappyAir we create projects for different pathologies or comorbidities and help people in selfcare plans with active living

MyAVA is a project which included integration an API, Virtual Assistant for Asthma self-care in adults.

These sort of IT solutions will advance and our experience in digital therapeutic care is very important in order to participate actively in R&D , production and in our case in deployment where we learn a great deal more from users about how they approach self-care.