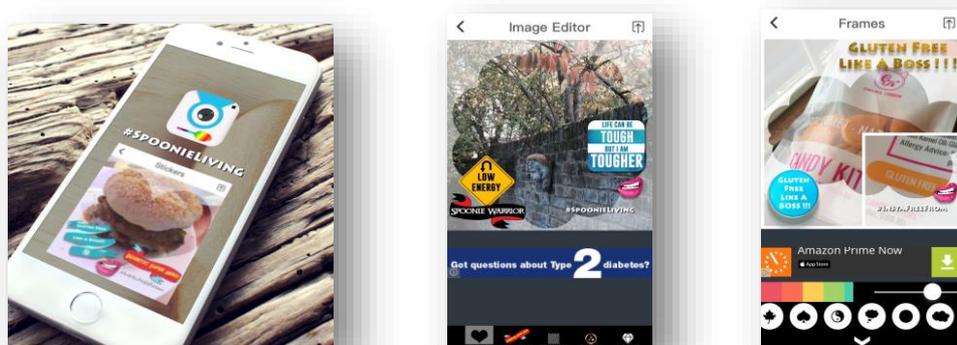


Self management of long term conditions within big social data: a study in the use of apps to help with the humanistic burden of coeliac disease

Today there are many smartphone photo apps like Instagram, where users can add filters to images before posting them on social media but there is a lack of image based apps with the option to share photos in relation to long term conditions or special diets, such as the gluten-free diet for coeliac disease. Sam Martin, PhD student and Coeliac UK funded researcher, has developed a smartphone pilot app called [Spoonie Living](#) to further explore how visual apps could help.

Professor Gary Wolf, cofounder of Quantified Self Labs, California, USA invited Sam to attend a two day [Workshop](#) on tracking and managing pain and symptoms of chronic diseases. The symposium provided a unique opportunity to show case and discuss the Spoonie Living app and to advance research in this area, as well as collaborate with those working at the cutting edge of this field.

Spoonie Living is an app that gives people with coeliac disease a visual tool to help them with the process of learning how to manage and express their symptoms and experiences. Individuals can use themed stickers and filters to tag photos of food and daily experiences of the condition – and go on to communicate their experience of self care via social media (e.g. Instagram, Twitter, Facebook).



Users can also communicate with each other from within the app, by posting images and leaving feedback / comments on each other's images, within the context of disease management, on the app's 'Wall of Fame'.

The app can also be applied in research studies with small groups of patients to produce group image diaries. This offers researchers and patients a way to use fairly comprehensive technology, via their smartphones, on a daily basis.

The Workshop covered both wearable technology and smartphone apps that allowed individuals to track or change their health related behaviour in the context of chronic pain / illness management. There was discussion around possible increased anxiety from focusing on and tracking pain and symptoms counter balanced with the positive benefits of using tools and techniques that enable a patient to become more aware of how they manage their self care.

Future work with this app will incorporate feedback to include:

- detailed analytical reporting with data export for users and researchers
- timeline data to better visualise adaption to self management

It is hoped that the Spoonie Living app and future versions will have the potential to help people with coeliac disease learn how to visually share the self management of their condition.