

# What do patients and carers need in health apps - but are not getting?

Results of a ...

- global survey of 1,130 patient and carers
- cross-stakeholder meeting on 12 November 2014, to help define concepts for new apps that address patient and carer unmet needs



# Acknowledgements

This white paper synthesises the input and feedback from patients' organisations, healthcare professionals, app developers, healthcare policymakers and regulators, the pharma, medtech and mobile technology industries, and academia to identify and help address patients' unmet needs in health apps. We are grateful for their insights and participation in the global survey into unmet needs (patients and carers) and workshop (all stakeholders).

## About PatientView and myhealthapps.net

A UK-based research, publishing and consultancy group, PatientView has been collecting and analysing the perspectives of thousands of patients on their healthcare since 2000. It now has the capacity to reach out to 120,000 patient organisations worldwide, covering over 1,000 specialities.

PatientView launched the myhealthapps.net website in November 2013 to provide an independent portal for patients, carers and health-conscious consumers to find apps that have been tried, tested and trusted by patient and health consumer groups. We gratefully acknowledge and would like to thank the many patients' organisations around the world which have contributed reviews of health and wellbeing apps to myhealthapps.net. A full list of current reviewers can be found on <http://www.myhealthapps.net/reviewers>.

We would also like to thank all our partners in myhealthapps.net and related research initiatives for their support and in the dissemination of this white paper – Digital Health and Care Alliance, European Connected Health Alliance, European Health Forum Gastein, Global Accessibility Reporting Initiative, GSK, Health 2.0, Janssen, NHS Health Apps Library, Telefonica and TICBioMed.

[www.patient-view.com](http://www.patient-view.com) · [www.myhealthapps.net](http://www.myhealthapps.net)

## About the GET project

The European project GET delivers services to eHealth SMEs and entrepreneurs in order to boost their growth and move them to the next level of competitiveness. One of the delivered services is the systematic identification of

'unmet needs' in Health. The objective is to support digital entrepreneurs to spot opportunities following a demand-driven approach (from the need to the solution) avoiding the technology push. The project also provides support regarding business modelling, internationalisation and private funding.



This project has received funding from the European Union's 7th Framework Programme for Research, technological development and demonstration under grant agreement no 611709.

[www.get-ehealth.eu/](http://www.get-ehealth.eu/)

## About TICBioMed

TICBioMed is a cooperative cluster of companies, universities, healthcare providers and public institutions that work together to foster technological innovation in healthcare (eHealth). The association participates in the European projects GET, READi for Health and FICHe, and is the organiser of the EU SME eHealth Competition.

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# Executive summary

The research for this project was undertaken in two steps. First, a global survey of patients and carers was conducted between July and October 2014. Respondents were recruited with the support of patient, disability and carers' groups worldwide, who completed an online questionnaire.

The results were presented at the Health 2.0 Europe conference in London, 12 November 2014. Second, a cross-stakeholder meeting was held during the conference to analyse the results of the survey focused on the five main areas identified by respondents — cancer, diabetes, disability (focusing on pain relief and management), mental health and wellness — and use the findings to try and define new concepts for apps in these fields.

## Stage 1: Global Survey

From June to October 2014 Patient View, in collaboration with Health 2.0, carried out a global study into what patients and carers want from healthcare apps. The survey involved people with long-term conditions, and aimed to:

- provide information to app developers about how to work with patients and healthcare professionals to improve apps to help meet unmet patient and carer needs
- identify specific examples of unmet needs across different therapy areas.

The survey concluded that patients and carers:

- are using apps but largely to gather information
- aspire to do a lot more with apps
- want to use technologies in conjunction with their healthcare professionals
- need guidance on which apps are best for them
- want understandable information on their medical symptoms and conditions.

### Snapshot of key survey results

Profile of respondents:

- 1,130 respondents (with either a long-term illness or caring for someone with one)
- From 31 countries (82.3% from Europe)
- The majority of respondents were affected by five therapy areas: diabetes, cancer, arthritis, mental health and rare diseases
- Almost 60% of respondents were in the 41-64 age range
- Almost 60% had their long-term condition, or cared for someone with one, for more than 10 years
- Almost 50% were interested in health campaigning (have an active interest in improving their health)
- 30% were active on social media channels focused on health
- Over 90% sought healthcare information via the internet
- 30% used health apps
- Just under 10% used sensors and other devices that they had bought
- 5% used monitoring devices supplied by their doctor/healthcare system.

Top 5 patient/carers wants from apps:

- To help them understand their condition and treatment choices (61%)
- To provide support (such as care planning) (55%)
- To track and monitor symptoms in order to benchmark their progress (46%)
- To provide a way to communicate with their doctor or nurse (45%)
- To raise public awareness of conditions which are important to them (38%).

Main barriers to using health apps:

- Confusion over the vast number of apps to choose from (37%)
- Uncertainty about which apps to use (32%)
- Preference for face-to-face interaction with doctors or nurses (31%)
- Lack of knowledge of health apps that may be relevant to them (30%)
- Lack of trust in health apps as unsure who develops or funds them (27%).

## Stage 2: Cross-stakeholder meeting

Following completion of the survey results, a roundtable meeting was organised at the Health 2.0 Europe conference in London on 12 November 2014, to facilitate inclusive patient-centred design from the start of the app creation process - including other factors which impact on the user, such as age, disability or social care needs - to define concepts for new apps addressing unmet needs in five core areas: cancer, diabetes, disability (focusing on pain relief and management), mental health and wellness.

The workshop gathered together 50 stakeholders who had a variety of roles, including: patients, carers, people with disabilities, app developers, clinicians, representatives of the pharma, medtech and telecoms industries, experts in medical communications and health education, and policymakers.

The participants were then allocated to one of the five roundtables, with a balanced mix of stakeholder perspectives, and asked to:

- review the unmet needs identified by the survey
- rank in order of importance these unmet needs
- identify potential ideas to address top ranking need(s) for their therapy area.

## Key summaries from each of the 5 therapy areas

Survey respondents were asked what they wanted from apps in their therapy area that they are not currently finding. The questions were open-ended so they could freely describe their own particular needs and preferences.

Taking the key need identified per therapy area from the survey results, the meeting participants then worked together to come up with design and concept features that their ideal app should have and identify the critical success factors.



### The key need identified

**An app that provides support in the management of my screening requirements and test results**

### Critical design and concept features that a cancer app should address

- Tracks my symptoms and informs me of tests needed, even books them for me
- Tracks tests, including blood pressure, temperature, sleep, mood, appetite
- Checks against my weight, size, nature of sleep - so everything seems appropriate
- Organises my test results to share with ALL my doctor/nurses and health clinics
- Has room for my medical information and records
- May conduct tests as well and help avoid biopsies when possible
- Keeps me up to date with research
- Communicates with health professionals
- Communicates with people in a similar situation

### Critical success factors identified

- Simplicity and usability of app design and content.
- Alignment of health apps with the needs of healthcare stakeholders, including medical professionals, through the prescription of health apps; insurance providers; patient and patient groups; and policymakers. To achieve this there needs to be better co-operation between developers and patients.



### The key need identified

**An intuitive app that calculates carb to insulin ratios advising on next best steps, giving feedback on how proper maintenance clearly improves my health** (relevant in Type 1 or insulin-dependent Type 2 diabetes only, though some aspects may be relevant to people with Type 2 diabetes that do not have to take insulin)

### Critical design and concept features that a diabetes app should address

- Calculates carb ratios, based on information provided by the user
- Provides useful information for understanding carb to insulin ratios
- Tracks my blood sugar levels regularly throughout the day
- Takes data on my symptoms, treatment and lifestyle
- Works out how the food I eat affects my blood sugar
- Works out how the exercise I take affects my blood sugar
- Must be easy to enter data
- Secure messaging service with doctors/nurses for questions would also be of value
- Supports me in calculating ratios and insulin dosing based on personal historical data
- Permits me to communicate with other people like myself to get help and advice on how much insulin to take with food
- Provides access to nutritional information for accurate carbohydrate content of common foods

### Critical success factors identified

- Successful diabetes health apps ought to draw on all the specific skills available in the field of diabetes, from endocrinologists to nutritionists, specialist diabetes nurses and diabetes educators.
- Materials need to be co-created between patients, healthcare professionals and developers.
- Apps should offer more predictive and personalised support.
- Regulation of apps needs to be modernised in light of new health app technology.





## Disability

The key need identified

**An app that provides a support package for pain management – improving upon what is already available**

**Critical design and concept features that a disability (pain) app should address**

- Tracks my levels of pain with simple measures (eg on a scale from 0 to 10, where 10 is worst) and in a way that makes me feel positive about the process
- Trackers to include blood pressure, energy/fatigue levels, mood, weight, sleep etc
- Tracks daily activities - such as diet, exercise, housework, CBT/meditation/mindfulness practice, socialising - which distract and may alleviate pain
- Trackers to include medicine use that may affect levels of pain
- Trackers to include environmental factors, such as weather, that may affect levels of pain
- Most important that the tracking allows me to spot trends and triggers
- Identifies whether the pain is part of my disease or not, and whether I need to seek more help
- Provides information about pain and how it may be alleviated for different medical conditions
- Could be used by the terminally ill
- Can be tailored for complex conditions
- Allows me to contact others and compare experiences
- Is shared with my doctor/nurse who can provide advice

**Critical success factors identified**

- A significant culture change needed within healthcare systems to overcome the primary barrier of connecting patients' apps with doctors' systems.
- Need for patients to see how they benefit from sharing their data, know what will happen to their data, have clear options about opting in/opting out, and sharing some parts of their data, but not others.
- Patient groups involved with pain that have been approached to help make apps often do not receive sufficient detail or a reason why the app needs developing; do not have their feedback acknowledged or taken into account; do not feel valued; do not know what happens to any information and comments they provide.



## Mental health

The key need identified

**An app that helps me manage a personal mental health crisis**

**Critical design and concept features that a mental health app should address**

- One that lets me log symptoms, such as changes in mood, weight, sleep patterns, or my medication so I can detect when a crisis is coming on, eg when I do not feel everything is as it should be
- Professional contacts to help me solve an emergency, such as a panic attack, or coping with a pre- or post-psychotic incident
- Information for the carer to help in a crisis situation
- Allows me to network with support groups that can help me
- Information so I understand my mental crises and triggers
- Online video contact with my doctor/nurse

**Critical success factors identified**

- Mental health patients need to be involved (with support from practitioners where necessary) from the concept stage of app development to make sure the app focuses on patients' priorities
- Validation process could be simplified as health professionals could agree on the "essential ingredients" needed in mental health apps rather than looking at individual apps one by one – giving app developers a clear, clinically-approved model to work to.
- App user would be in control, giving them flexibility in setting permissions, particularly if he/she does not want family involved in their network or community, and in some cases may see their family as part of the problem. On the other hand the individual user may rely on trusted others to spot their own characteristic, individual warning signs that a crisis is approaching.



## Wellness

### The key need identified

### An app that provides feedback on how treatment, care and lifestyle changes impact my health and wellbeing

#### Critical design and concept features that a wellness app should address

- Lets me select from a comprehensive list of healthy lifestyle choices (relevant to my condition)...
- Lets me choose the ones I want to adopt
- Once I make my lifestyle choices, reminds me what I should do when (eg drink enough water, take a tablet)
- Combines the lifestyle tracked with symptom/wellness logger\*
- Helps me understand whether my condition is stable and whether I am making the right lifestyle choices
- Provides advice on how to improve on my situation (at the end of every week)
- Ensures that self-monitoring helps me deal with problems as they arise, and provides emergency contacts
- Arranges the information I collect so it is useful to my doctor/nurse, ensuring my data can be shared
- Communicates with health professionals I choose to talk to about my progress, but they should work as a team
- Connects with the right patient/carer support groups for me to talk about my progress
- Is tailorable for complex conditions
- Helps carers support the patients they help

#### Critical success factors identified

- Apps should be easy for the patient to use anywhere.
- Important to take a long-term view, and track trends.
- Ability to keep data when changing/upgrading mobile devices.
- The patient also needs to control which wellness information they share with whom and for what purpose. Conditions need to be defined about when and where data are to be shared.

### Conclusions and next steps

If any conclusion could be reached from the entire project it was that despite sharing a mutual aim to improve the quality of health apps from patient and public perspectives, to involve patients more in the creation process and foster greater trust in apps, differences among stakeholders were sometimes too great to make the process viable, and the challenges too ill-defined to be resolved. Health professionals were surprised that patients sometimes had such a separate agenda, that they thought could only be understood and expressed by patients and users. App developers had difficulty translating some of the very broad objectives articulated by patients and consumers in the survey.

Clearly a tool needs to be developed that enables stakeholders to engage and understand user perspectives in a more systematic fashion. For this reason PatientView/myhealthapps.net is resolved, as a next step, to develop a set of guidelines, evolving over time, which will define what patients and carers want from health apps. The first generation of guidelines will be published later in 2015.







# Introduction

From the consumer perspective, the big promise of health apps is not only gaining support with diagnosis and treatment but also help with greater self-care.

Today, less than half of patients with a long-term illness take exercise, have a social life, get enough sleep, cope with stress well, eat a healthy diet or look for health information online—according to an April 2014 EU-wide pilot study on the opinions of patients with long-term conditions (and their carers) [*PatientView study commissioned by the European Commission and the Greek Presidency of the Council of the EU: Survey of 500 respondent patients/carers on the value of services in the home to support independent living and care for people with a long-lasting illness, April 2014*<sup>1</sup>].

**The big promise of health apps is support on demand to help with greater self-care.**

Thus any technology that promotes healthier lifestyles is, in principle, to be highly welcomed. With the onset of wearables, ever more sophisticated Bluetooth® technology, and the miniaturisation of batteries, the prospect of population-wide adoption of mHealth gadgets does not look far-fetched. Indeed, health policymakers are hoping that mHealth interventions could bring about significant reductions in levels of chronic disease enough to stave off the impending crisis in over-stretched healthcare systems—and all this, without draining the public purse.

But—and it is a big but—while consumer acceptance of health apps and other dimensions of mHealth, has been initially enthusiastic, significant barriers will have to be overcome before it can be declared healthcare's hoped for game-changer.

The responses from 211 different stakeholders to the public consultation on the EU's Green Paper on mHealth [*Summary report on the public consultation on the Green Paper on mobile health, published 12 January 2015*<sup>2</sup>] identified seven major areas of concern with mobile health apps that need to be addressed before the technology can go mainstream. These were: (i) the need for clarity on levels of data security to protect public and patients, (ii) lack of appropriate governance of lifestyle (non-medical)

health apps, (iii) possible threats to patient safety, (iv) lack of transparency about who lies behind an app, (v) lack of clinical input and integration with healthcare systems, (vi) lack of clarity about whether health apps produce positive outcomes, and (vii) the ill-funded nature of the entire enterprise that surrounds app development.

According to Jorge Gonzalez, of TICBioMed—an eHealth cluster headquartered in the region of Murcia (Spain) whose members include the local public healthcare system, four private hospitals, three universities and more than 30 ICT companies—one reason why the health app market has failings is that more often than not health apps are developed in isolation from their intended users: patients and the public.

Developers are motivated more by the cleverness of a technology or idea than improvements in health outcomes. Indeed, when health apps users were asked about what they need from health apps (the topic of the survey in this white paper) patient and carers declare themselves confused by the huge number of health apps they can choose from and are uncertain what value they offer (see Chart 9, page 13).

Patients also worry that health apps will replace face-to-face consultations with doctors or nurses and that the data collected in their health apps might be used for other purposes of which they are unaware. The high turnover of health apps and their short shelf-life is evidence of users' concerns. Then there is the fact that very few health apps are integrated with healthcare systems. Worse still, health apps mostly work in isolation from one another and are generally not interoperable.

For this reason public and patient engagement needs to lie at the heart of any strategy designed to overcome the significant problems that sit at the core of health app development and which are prohibiting more uptake and better use of health apps by consumers. Hence this latest piece of research from PatientView, myhealthapps.net, GET, Health 2.0, TICBioMed and all their partners. The purpose of the research outlined in this White Paper is to help clarify more precisely what it is patients and the public want from health apps, with a focus on five main areas of app development: cancer, diabetes, disability (focusing on pain relief and management), mental health and wellness.



# The global survey

Results are summarised below:

## Profile of respondents

1,120 respondents from 31 countries and almost 50 therapy areas were represented in the survey responses:

- |                                     |                                 |
|-------------------------------------|---------------------------------|
| ■ 10% with diabetes                 | ■ 4.9% with a hormonal disorder |
| ■ 9.6% with cancer                  | ■ 4.8% with pain                |
| ■ 7.6% with arthritis               | ■ 4.4% with a heart condition   |
| ■ 6.6% with a mental health problem | ■ 4.2% with multiple sclerosis  |
| ■ 6.4% with a rare disease          | ■ Plus: 39 other conditions     |
- .....



Chart 1: The majority of respondents were patients. Carers accounted for one in four of all responses, while one in ten were both patients and carers.

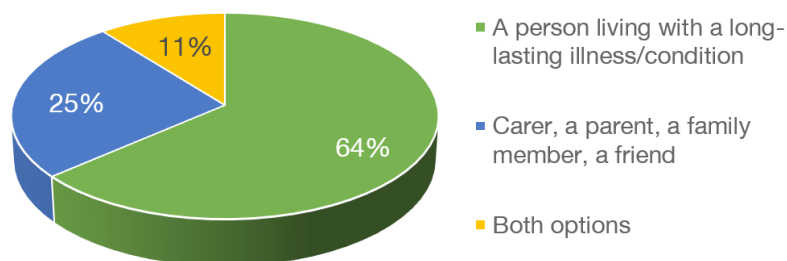


Chart 2: Nearly 60% of respondents were in the age range of 41-64.

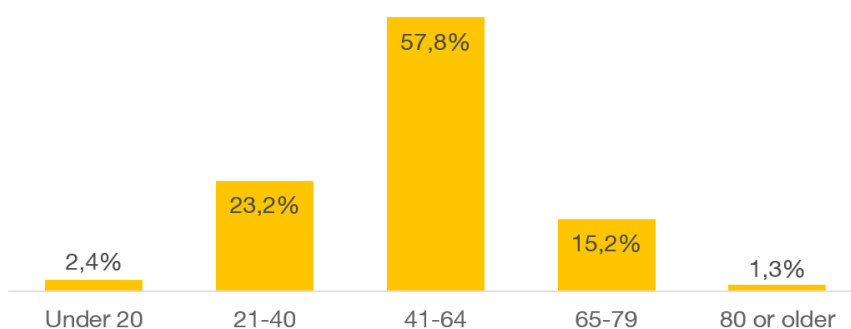


Chart 3: Nearly 40% had had their long-term condition, or cared for someone with one, for more than 10 years.

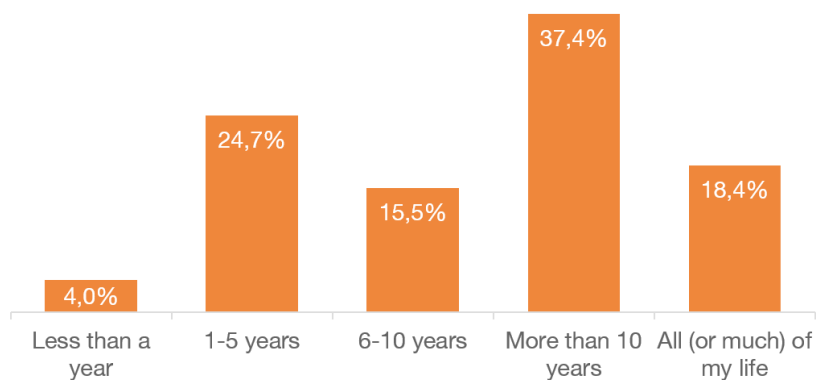
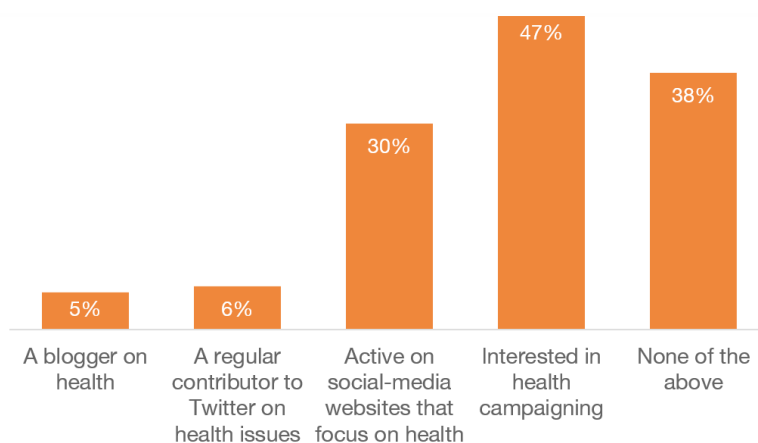
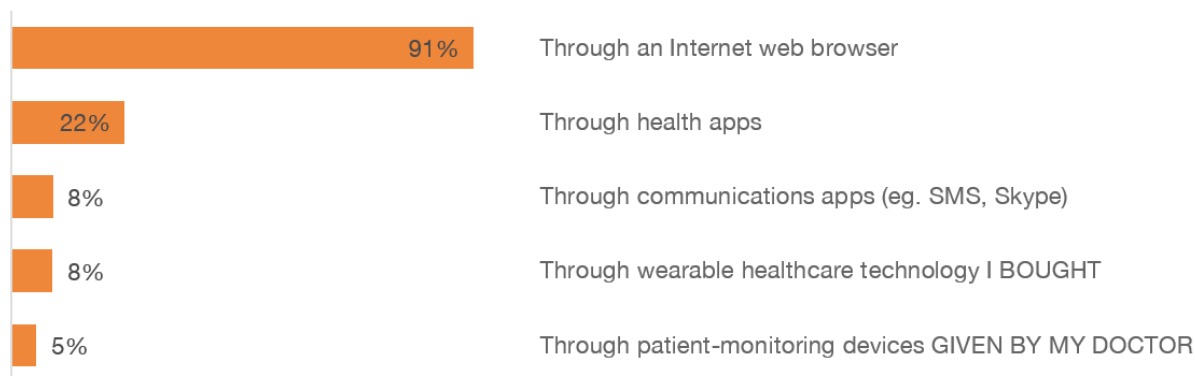


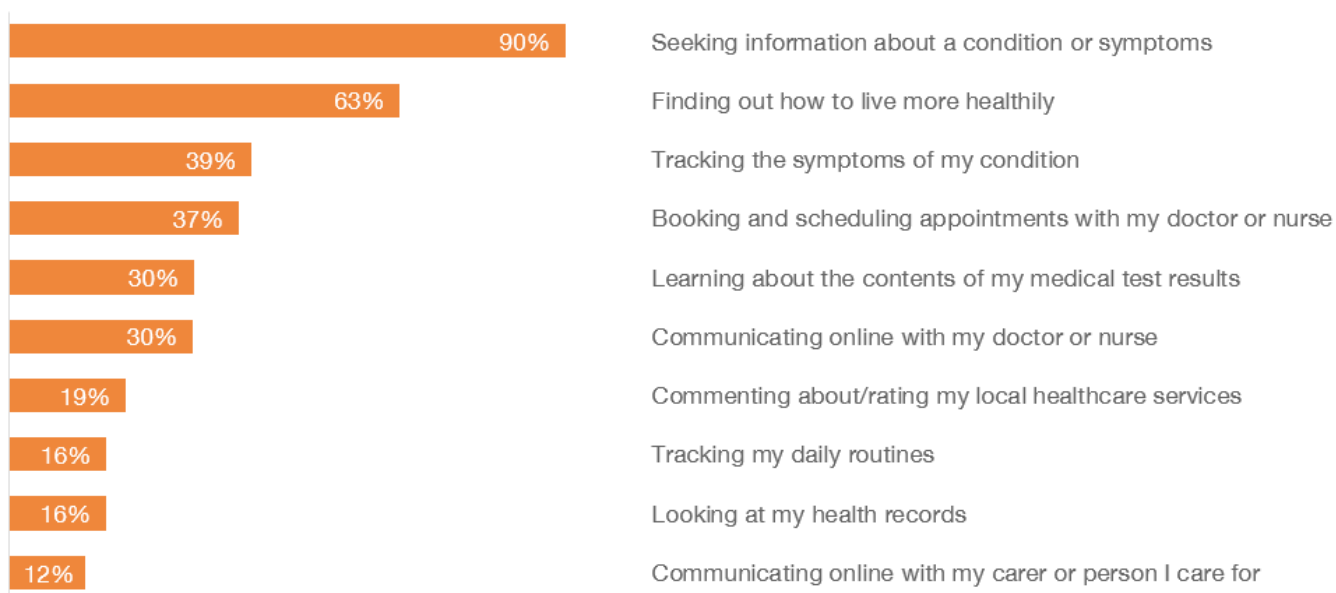
Chart 4. Nearly half of all respondents were active in trying to improve their health by using electronic facilities.



**Chart 5: 30% of patients and carers were using health apps as the main way of getting involved with healthcare electronically – if wearable technologies are included.**



**Chart 6: Health apps are primarily used to seek information.**



**Chart 7: Patients and carers are also regularly using apps to support better self-care and to network with fellow sufferers.**

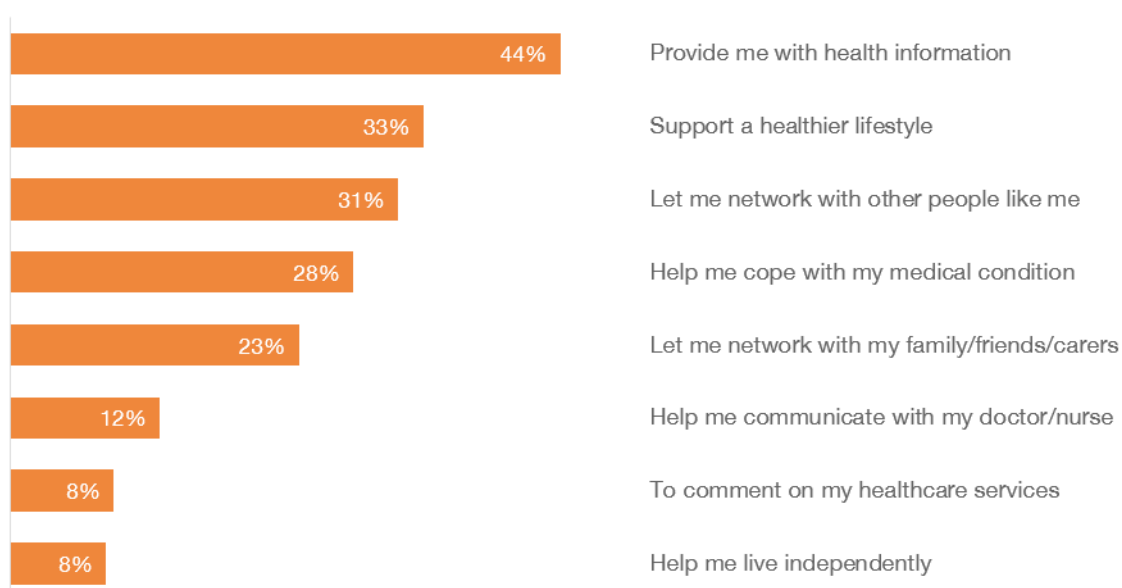




Chart 8: But patients and carers want more from apps—they want to be able to understand their medical condition and treatments, they require practical support such as care planning and they want to be able to communicate with their doctor/nurse.



Chart 9: Significant barriers to health app use exist from the patient perspective: too many apps to choose from, not enough certainty that they offer any value, and concern that they will replace face-to-face consultations with doctors or nurses.

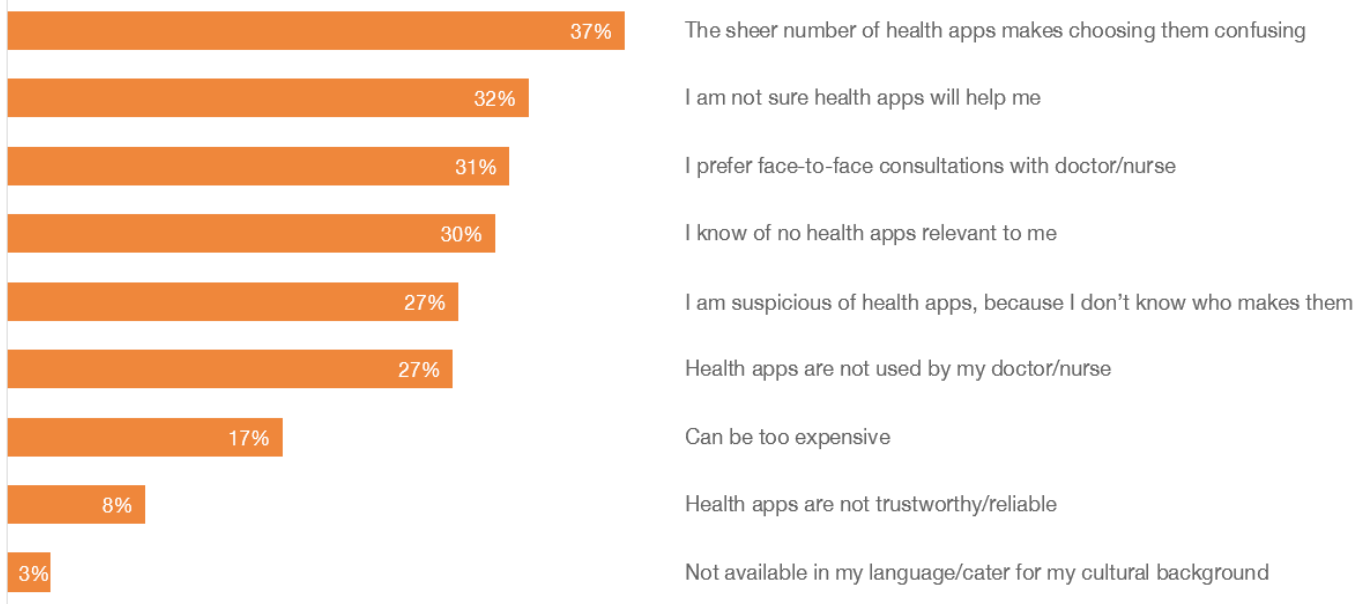


Chart 10: The main single concern of patients and carers is whether they can trust the app to provide accurate information and guarantee the safety of their data.

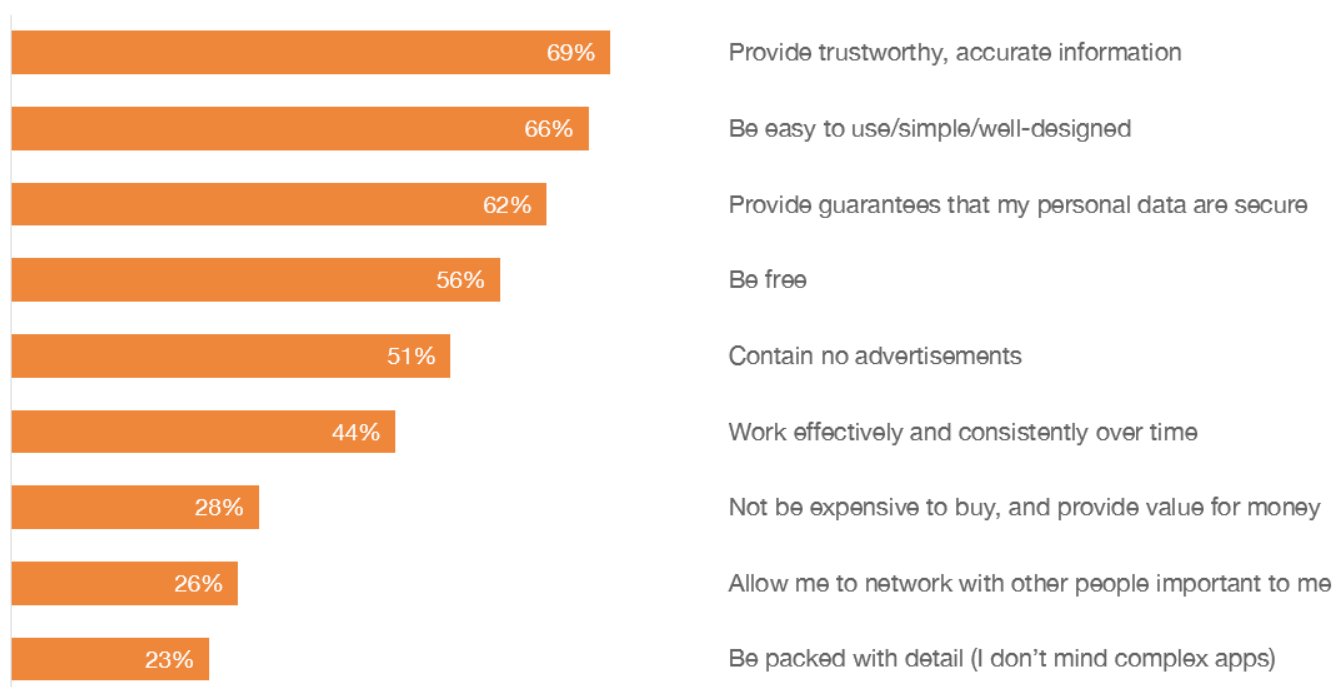


Chart 11: According to patient and carers health apps' real value lies in helping patients and carers to better understand and self-manage their condition(s).



# Health apps: unmet needs in five therapy areas

Analysis of the survey results revealed five main therapy areas where there are currently significant unmet needs: cancer, diabetes, disability/pain, mental health and wellness.



Cancer



Diabetes



Disability/pain



Mental health



Wellness

# Cancer

## What do respondents involved with cancer want from apps?

- 61% want to understand more about medical conditions and choices of treatments
- 46% want practical support (such as care planning)
- 43% want a way of communicating more regularly with the doctor or nurse
- 40% want to comment (give feedback) on the healthcare services I receive
- 39% want to be able to track my symptoms/lifestyle/feelings etc and know if I am improving or not
- 39% want to stop feeling isolated, and want the app to help me reach out to other people
- 38% want support at the right time, such as by issuing me with reminders and other information
- 34% want help to raise public awareness about diseases/conditions important to me
- 33% want emotional support
- 20% want the app to be less expensive for me than other forms of healthcare support.

## What would make respondents involved with cancer use apps regularly?

### Apps that ...

- provide trustworthy, accurate information (68%)
- are easy to use (65%)
- provide guarantees that my personal data are secure (unless I choose to pass on my data, for instance, to my doctor) (63%)
- are free (56%)
- contain no advertisements (55%)
- work effectively and consistently over time (43%)
- are packed with detail (I don't mind complex apps) (27%)
- allow me to network with other people important to me (24%)
- are not expensive (23%)

The highest price paid for an app by any respondent is US\$2,500, but the majority have paid zero.

## Examples of good apps, according to respondents involved with cancer

Access to clinical schedules	Epic Haiku - only for Epic's Electronic Health Record
Access to medical records and health clinic	061 CatSalut Respon (in Catalonia, Spain); Hello Health (Canada)
Communicating with people like me	Liv med Kræft [Life with Cancer] (Denmark)
Exercise	Lose it; myfitnesspal
Heart rate	Instant Heart Rate monitor
Organising treatment and care	My organiser - Macmillan
Finding services	Toiletten-Finder Apps Erste Hilfe Apps; SmallTalk Oral Motor Exercises
Medical information	WebMd
Nutritional advice	Fooducate
Understanding my condition	Visual anatomy

## Profile of respondents

93 respondents involved with cancer including bowel, brain, breast, colon, stromal, Lynch syndrome, multiple myeloma, prostate and Waldenstrom macroglobulinemia

- 59 living with cancer
- 10 are both patient and carer
- 24 are carers/family/friends

### From 12 countries

Austria 1; Bulgaria 1; Canada 11; Denmark 3; France 8; Germany 7; Netherlands 1; Norway 6; Portugal 1; Spain 8; UK 28; USA 18





## Areas of unmet need

### An app that provides support in the management of my screening requirements and test results

Respondents were asked open-ended questions so they could freely describe their own particular needs and preferences.

- Tracks my symptoms and informs me of tests needed, even books them for me
- Tracks tests, including blood pressure, temperature, sleep, mood, appetite
- Checks against my weight, size, nature of sleep - so everything seems appropriate
- Organises my test results to share with ALL my doctor/nurses and health clinics
- Has room for my medical information and records
- May conduct tests as well and help avoid biopsies when possible
- Keeps me up to date with research
- Communicates with health professionals
- Communicates with people in a similar situation



# Diabetes

## What do respondents involved with diabetes want from apps?

- 59% want to understand more about medical conditions and choices of treatments
- 55% want practical support (such as care planning)
- 52% want a way of communicating more regularly with the doctor or nurse
- 49% want to be able to track my symptoms/lifestyle/feelings etc, and know if I am improving or not
- 48% want support at the right time, such as by issuing me with reminders and other information
- 35% want to comment (give feedback) on the healthcare services I receive
- 31% want help to raise public awareness about diseases/conditions important to me
- 25% want the app to be less expensive for me than other forms of healthcare support
- 23% want emotional support
- 21% want to stop feeling isolated, and want the app to help reach out to other people.

## What would make respondents involved with diabetes use apps regularly?

### Apps that ...

- provide trustworthy, accurate information (70%)
- provide guarantees that my personal data are secure (unless I choose to pass on my data, for instance, to my doctor) (65%)
- are easy to use (64%)
- are free (56%)
- contain no advertisements (51%)
- work effectively and consistently over time (48%)
- are not expensive (31%)
- are packed with detail (I don't mind complex apps) (27%)
- allow me to network with other people important to me (22%)

The highest price paid for an app by any respondent is GBP 2,900. One person commented "I would pay as much as is necessary if the app was guaranteed to work independently"

## Examples of good apps, according to respondents involved with diabetes

Carb and calorie information	Carbs and calcs
Carb information for blood glucose	Glycemic Index
Dose adjustment for normal eating (DAFNE)	DAFNE app (for Type 1)
Exercise	Noom Walk; Fitbit; myFitnesspal
Feedback on improving blood glucose maintenance	MySugr; SocialDiabetes
General lifestyle support	S Health (Samsung)
Medical information	Medscape
Professional device via the mobile/iPad	FEDEDiabetes (Spanish); iTriage; Whatsapp (messenger service)
Tracking and monitoring	myLifestyle (Diabetes UK); Diabetesdagboek (Diabetes Diary - Netherlands); Glooko; Glucose Buddy; Healthsome G; +iBigStar; MySugr; FEDEDiabetes (Spanish); DiabetesConnect; Diabetes Plus; Diabetes & Blood Pressure App
Treatment /medicine information	Medikamente-per-klick
Weight control	Noom Coach; Gewichtskontrolle Lite

## Profile of respondents

96 respondents involved with diabetes

- 74 living with diabetes
- 8 are both patient and carer
- 14 are carers/family/friends

### From 14 countries

Austria 5; Bulgaria 1; Canada 1; Germany 3; Ireland 1; Mexico 2; Norway 2; Poland 1; Portugal 1; Romania 1; Spain 5; Sweden 1; UK 64; USA 8



## Areas of unmet need

### An app to calculate carbohydrate to insulin ratios advising on next best steps

Respondents were asked open-ended questions so they could freely describe their own particular needs and preferences.

- Calculates carb ratios, based on information provided by the user
- Provides useful information for understanding carb to insulin ratios
- Tracks my blood sugar levels regularly throughout the day
- Takes data on my symptoms, treatment and lifestyle
- Works out how the food I eat affects my blood sugar
- Works out how the exercise I take affects my blood sugar
- Must be easy to enter data
- Secure messaging service with doctors/nurses for questions would also be of value
- Supports me in calculating ratios and insulin dosing based on personal historical data
- Permits me to communicate with other people like myself to get help and advice on how much insulin to take with food
- Provides access to nutritional information for accurate carbohydrate content of common foods.



# Disability/pain

## What do respondents involved with pain management want from apps?

- 65% want to understand more about medical conditions and choices of treatments
- 64% want practical support (such as care planning)
- 64% want to be able to track my symptoms/lifestyle/feelings etc and know if I am improving or not
- 53% want a way of communicating more regularly with the doctor or nurse
- 51% want help to raise public awareness about diseases/conditions important to me
- 49% want support at the right time, such as by issuing me with reminders and other information
- 39% want emotional support
- 38% want to stop feeling isolated, and want the app to help me reach out to other people
- 36% want to comment (give feedback) on the healthcare services I receive
- 35% want the app to be less expensive for me than other forms of healthcare support

## What would make respondents seeking pain relief use apps regularly?

### Apps that ...

- provide trustworthy, accurate information (77%)
- provide guarantees that my personal data are secure (unless I choose to pass on my data, for instance, to my doctor) (76%)
- are easy to use (71%)
- are free (60%)
- work effectively and consistently over time (58%)
- contain no advertisements (56%)
- are not expensive (41%)
- are packed with detail (I don't mind complex apps) (31%)
- allow me to network with other people important to me (28%)

## Examples of good apps, according to respondents interested in pain relief

Diet	The Monash Uni Low FODMAP Diet; Perfect Diet Tracker
Exercise	MyFitnessPal; Runtastic
Pain management	CatchMyPain; Manage my pain Lite; My Pain Diary: Chronic Pain Management; Pain Care;
Medication tracker	Med Helper Pro
Medical information	WebMD
Tracker for activity, diet and sleep	UP by Jawbone
Symptom checker	Isabel Symptom Checker
Weight	Lose it; Perfect Diet Tracker
Other vital signs	Period tracker

## Profile of respondents

77 respondents involved with pain relief

- 58 patient
- 9 are both patient and carer
- 8 are carers/family/friends

### From 8 countries

Canada 6; Czech Republic 1; Germany 4; Ireland 2; Spain 3; Switzerland 1; UK 51; USA 9





## Areas of unmet need

**An app that provides a support package for pain management – improving upon what is already available**

Respondents were asked open-ended questions so they could freely describe their own particular needs and preferences.

- Tracks my levels of pain with simple measures (eg on a scale from 0 to 10, where 10 is worst) and in a way that makes me feel positive about the process
- Trackers to include blood pressure, energy/fatigue levels, mood, weight, sleep etc
- Tracks daily activities such as diet, exercise, housework, CBT/meditation/mindfulness practice, socialising, which distract and may alleviate pain
- Trackers to include medicine use that may affect levels of pain
- Trackers to include environmental factors such as weather that may affect levels of pain
- Most important that the tracking allows me to spot trends and triggers
- Identifies whether the pain is part of my disease or not, and whether I need to seek more help
- Provides information about pain and how it may be alleviated for different medical conditions
- Could be used by the terminally ill
- Can be tailored for complex conditions
- Allows me to contact others and compare experiences
- Is shared with my doctor/nurse who can provide advice.



# Mental health

## What do respondents involved with mental health conditions want from apps?

- 63% want practical support (such as care planning)
- 56% want support at the right time, such as by issuing me with reminders and other information
- 48% want to understand more about medical conditions and choices of treatments
- 47% want emotional support
- 45% want a way of communicating more regularly with the doctor or nurse
- 39% want to be able to track my symptoms/lifestyle/feelings etc, and know if I am improving or not
- 36% want to stop feeling isolated, and want the app to help reach out to other people
- 36% want help to raise public awareness about diseases/conditions important to me
- 34% want to comment (give feedback) on the healthcare services I receive
- 19% want the app to be less expensive for me than other forms of healthcare support.

## What would make respondents involved with mental health conditions use apps regularly?

### Apps that ...

- provide trustworthy, accurate information (73%)
- are easy to use (67%)
- are free (59%)
- provide guarantees that my personal data are secure (unless I choose to pass on my data, for instance, to my doctor) (56%)
- contain no advertisements (55%)
- work effectively and consistently over time (52%)
- are not expensive (33%)
- allow me to network with other people important to me (33%)
- are packed with detail (I don't mind complex apps) (19%)

The highest price paid for an app by any respondent is GBP 1,500, but the majority have paid zero.

## Examples of good apps, according to respondents with an interest in mental health

Booking and managing appointments	Patient access
Charting/logging symptoms or behaviour	Mood charting; Buddy App
Communicating with carers	Jointly; WhatsApp Messenger
Communicating with health professionals	Medeo (from Canada)
Dealing with symptoms	MindShift (for anxiety)
Exercise and lifestyle	My fitness pal; Weight Watchers
Logging meals	Recovery record (for eating disorders)
Medical information	Medscape
Medicine information	Drugs & Medications
Professional advice	iCouch

## Profile of respondents

64 respondents involved with mental health conditions including anxiety, bipolar disorder, eating disorders, schizophrenia and Tourette's

- 23 living with a mental health problem
- 12 are both patient and carer
- 29 are carers/family/friends

### From 12 countries

Austria 1; Bulgaria 1; Canada 3; France 1; Germany 9; Greece 1; Ireland 1; Netherlands 1; Spain 7; Switzerland 1; UK 25; USA 13





## Areas of unmet need

### An app that helps me manage a personal mental health crisis

Respondents were asked open-ended questions so they could freely describe their own particular needs and preferences.

- One that lets me log symptoms, such as changes in mood, weight, sleep patterns, or my medication so I can detect when a crisis is coming on, eg when I do not feel everything is as it should be
- Professional contacts to help me solve an emergency like a panic attack, coping with pre- or post-psychosis
- Information for the carer to help in a crisis situation
- Allows me to network with support groups that can help me
- Information so I understand my mental crises and triggers
- Online video contact with my doctor/nurse.



# Wellness

## What do respondents involved with wellness want from apps?

- 100% want to be able to track my symptoms/lifestyle/feelings etc, and know if I am improving
- 71% want to understand more about medical conditions and choices of treatments
- 66% want practical support (such as care planning)
- 58% want support at the right time, such as by issuing me with reminders and other information
- 56% want a way of communicating more regularly with the doctor or nurse
- 42% want help to raise public awareness about diseases/conditions important to me
- 41% want to comment (give feedback) on the healthcare services I receive
- 38% want to stop feeling isolated, and want the app to help reach out to other people
- 36% want the app to be less expensive for me than other forms of healthcare support
- 35% want emotional support.

## What would make respondents, seeking improved levels of wellness, use apps regularly?

### Apps that ...

- provide trustworthy, accurate information (79%)
- provide guarantees that my personal data are secure (unless I choose to pass on my data, for instance, to my doctor) (75%)
- are easy to use (74%)
- are free (61%)
- work effectively and consistently over time (58%)
- contain no advertisements (57%)
- are not expensive (25%)
- allow me to network with other people important to me (33%)
- are packed with detail (I don't mind complex apps) (31%)

## Examples of good apps, according to respondents seeking improved levels of wellness

Access to health professionals	Patient Access (booking appointments, viewing medical records, ordering repeat prescriptions, UK)
Continence issues	Various toilet finder apps
Diary	Mac Calendar
Diet and fitness	Carbs and Calories; Ernaehrung Pro (German); Loseit; Noom Coach; MyPlate Calorie Tracker; Perfect Diet Tracker (Windows only); The Monash University Low FODMAP Diet [For IBS patients only]
Exercise and fitness tracker	C25K running app; DailyBurn; Fitbit; health Mate (Withings); Moves; Myfitnesspal; MyPlate Calorie Tracker; Runkeeper; Runtastic; SATS Elixia app; Loseit
First aid	Erste Hilfe DRG (German); ICE Standard (includes a record of the drugs I am taking)
Keeping healthy	My Lifestyle (Maltese)
Medication tracker and reminder	Dosecast; Med helper Pro; Medhelper; MediSafe; MedTracker; Your Medicine 1-2-3 Pro
Mental health support	iCouch
Preparing for doctors' visits	DocReady (mental health)
Sleep	UP band and app (with Apple's Health App)
Tracker daily activities and vital signs	Apple dashboard; Headache Diary; Life cycle-Period,Ovulation & Fertility calendar; My charts (blood pressure, pulse); WaterMinder
Tracker symptoms and feedback	Buddy (mental health only); Symple
Understanding of my medication/condition	CVS Pharmacy app; Epocrates (for drug interactions); iDoctus (Spanish, primarily for doctors); Merck manual; WebMD
Weight tracker	Gewicht bijhouden (Dutch)

## Profile of respondents

518 respondents

- 341 patient
- 65 are both patient and carer
- 112 are carers/family/friends

### From 23 countries

Argentina 3; Austria 3; Belgium 3; Bulgaria 3; Canada 19; Denmark 7; France 11; Germany 28; Greece 1; Ireland 23; Mexico 1; Moldova 1; Netherlands 5; Netherlands Antilles 1; Norway 5; Poland 1; Portugal 2; Spain 37; Sweden 1; Switzerland 1; UK 278; Uruguay 1; USA 79





## Areas of unmet need

### An app that provides feedback on how lifestyle changes impact my health and wellbeing

Respondents were asked open-ended questions so they could freely describe their own particular needs and preferences.

- Lets me select from a comprehensive list of healthy lifestyle choices (relevant to my condition)
- Lets me choose the lifestyle changes I want to follow
- Once I make my lifestyle choices, reminds me what I should do when
- Combines the lifestyle tracked with symptom/wellness logger
- Helps me understand whether my condition is stable and whether I am making the right lifestyle choices
- Provides advice on how to improve on my situation
- Ensures that self-monitoring helps me deal with problems as they arise, and provides emergency contacts
- Arranges the information I collect so it is useful to my doctor/nurse, ensuring my data can be shared
- Communicates with health professionals I choose to talk to about my progress
- Connects with the right patient/carer support groups for me to talk about my progress
- Is tailored for complex conditions
- Helps carers help the patients they help.



# The stakeholder workshop

## Key outcomes of the roundtable discussions

Following completion of the survey results, a roundtable meeting was organised by PatientView, together with the European project GET represented by TICBioMed and Health 2.0, and held at the Health 2.0 Europe conference in London on 12 November 2014. The aim was to help define concepts for new apps addressing unmet needs in five core areas: cancer, diabetes, disability (focusing on pain relief and management), mental health, and wellness.

The workshop gathered together 50 stakeholders who had a variety of roles, including: patients, people with disabilities, app developers, clinicians, representatives of the pharma, medtech and telecoms industries, experts in medical communications and health education, and policymakers.

Each stakeholder was allocated to one of the five roundtables reviewing the different zspecialty areas: cancer, diabetes, disability (pain management), mental health and wellness.

Participants were then asked to:

- review the unmet needs identified by the survey.
- rank in order of importance these unmet needs.
- identify potential ideas to address top ranking need(s) for their therapy area.



# Common themes and challenges

Although each of the five groups focused on different therapy areas, common themes emerged across group discussions tackling:

1. The desirable trends stakeholders would like to see emerging in the health apps market.
2. Drivers and barriers for health app development.
3. The importance of sustainable health apps.
4. The importance of personalisation in health apps.
5. How apps can be made more viable from a user perspective.
6. The need for more robust business model to finance health apps.



## 1. Desirable trends in health apps as follows:

From	To
Being too technically focused [apps determined by what is technically available]	Patient and carer focus: apps focused on what patients, carers and the public need most
Apps as trackers and ways of recording data	Apps integrated into wider self-management support
Fragmentation, with many 'stand-alone' apps	Apps as part of increasingly integrated healthcare solutions
Isolated user	Users able to build a support network around themselves, deciding how to involve healthcare professionals, other patients and carers
Non-transparent privacy and data risk	More transparency about data sharing, determined and defined by the patient
Isolated technology at risk when patient changes phone or software updates.	Linked technology: apps transferable across platforms and versions of software without loss of data.

## 2. Drivers and barriers for health app development

Drivers	Barriers
Cost and resource pressures on health services and insurers	Data protection regulation and its practical implementation
Culture change within healthcare providers towards promoting preventive health and earlier intervention	Lack of sustainable business models for health app development
Technological capability and improving usability	Lack of access during app development to stakeholders including patients, clinicians, and carers
Patients and carers increasingly use the technology day-to-day.	Privacy risks to patients, including unwilling or unknown sharing of data.

## 3. On the importance of sustainable health apps

A common concern raised by stakeholders at the roundtable is the risk of a health app disappearing or ceasing to work once the patient had started to build it into their health routines. Across the groups, the participants identified five essential 'pillars' to help ensure the sustainability of healthcare apps: financial, technological, clinical, integrated and apps that last 'for life'.

**Five essential pillars to help ensure the sustainability of healthcare apps: financial, technological, clinical, integrated and apps that last ‘for life’**

Sustainable healthcare app				
Financial	Technological	Clinical	Integrated	‘For life’
Sustainable business model, for example subscription, payer contribution	Works seamlessly over multiple platforms  Smooth updates with no loss of data or negative impact on patients	Accepted by HCPs and patients because medical content is accurate, and regularly reviewed and updated	Accepted as part of the local healthcare support system  HCPs, patients and carers clear how this app fits into the person’s care	Able to adapt and target personalised support for a patient at each stage of a journey with a long-term condition

#### 4. The importance of personalisation in health apps

Another key issue raised at the roundtable meeting was how apps could adapt to and address an individual’s changing needs as they:

- increasingly manage their own health
- progress with a long-term condition

The groups identified a range of factors driving the need for greater personalisation in healthcare apps and possible solutions to how health apps might deal with the complexities of bespoke public and patient demands. People need:

- to be confident and able to self-manage, including their health literacy
- be capable of making informed choices in using and updating technology, including their e/mHealth literacy
- to account for differing patient experiences with a medical condition or user experiences when healthy
- to be able to cope with a complex interaction of co-morbidities and complications as their condition progresses
- support from the local healthcare system, with treatment pathways, resources and measures often varying depending on where they live.

#### 5. How apps can be made more viable from a user perspective

All the groups recognised that apps could be made more useful to users.

How to make health apps more user friendly:

- identify and target a specific unmet patient priority
- involve patients, carers, healthcare professionals at each stage of the app’s development, making sure it is in line with their needs
- update with patient feedback, medical updates, or the need for technology updates, for example using crowd sourcing.

#### 6. The need for more robust business models to finance health apps

At present there appears to be no viable business model for funding health apps –other than charging for the app itself.

The groups explored ways to finance the development of a health app:

- Grants, typically offered to a developer by a company willing to fund an app. The idea behind the app, and ownership of the app may come from either party
- Subcontracting, for example, where a pharmaceutical company subcontracts the app’s development to a developer
- Crowdfunding, which typically may go to the start-up company behind the health app, rather than just financing the development of the health app itself
- Self-developed health apps, typically created by a patient who has personal experience of a condition
- Subscription, to enable ongoing finance for updates. This can also give a structure to turn off apps that have become obsolete, or which are falling foul of changing legislation.
- Least popular was for the health app to be free, where the developer raises revenue through the sale of patient data collected on the app.



# Group suggestions for apps for five specific therapy areas

In five discussion groups, conversations focused about the core needs of patients or public for the specific therapy area/specialty being reviewed, the barriers to using health apps and factors that might promote usage of health apps by patients or the public.



## Cancer

### The challenge raised in the survey and topic of discussion:

**An app that provides support in the management of my screening requirements and test results**

#### Prioritising patients' unmet needs

The group agreed an ideal app would be a symptom tracker, coupled with a reminder when tests are needed, which communicates with health professionals and enables communication with peers. The tracker would also provide screening and test results, as well as information and support relevant for different stages of the patient's cancer experience.

#### Core needs

Apps need to be fine-tuned to patient experiences and also support patients with cancer in self-management of their condition. When tracking data, patients in the initial stage of cancer may not require much tracking, while those in remission might want to see more. The tracking facility of any health app could include information on whether the patient's health/medical data "met expectations" at that particular point—in other words whether data inputted by the patient matches the predicted patient situation during or after treatment. Included should be support mechanisms helping adherence to cancer treatment; understanding why and how to take cancer treatments to minimise their possible side-effects.

#### Barriers to using health apps

When asked to define the obstacles that prevent patients from downloading, or using health apps, the group believed there are too many health apps for patients to be able to distinguish the right apps for them. The health apps may be too generic, and not relevant to individual patients.

Patients may not recognise the benefits and the value apps could have for them. Many health apps have not yet proven themselves. There are also privacy concerns—patients' fears that personal health data stored by the app may not be secure and may be passed on, even sold. The group discussed health professionals' reluctance to prescribe apps, which is possibly due to concerns about patient safety if the app is not clinically validated or certified—or there may be concerns that prescribing apps might impact on doctors' budgets.

#### Critical success factors identified

Two factors were believed to dictate success in a health app for people with cancer (1) Simplicity and usability of app design and content; (2) Alignment of health apps with the needs of healthcare stakeholders, including medical professionals, through the prescription of health apps; insurance providers; patient and patient groups; and with policymakers. To achieve this there needs to be better co-operation between developers and patients.







# Diabetes

## The challenge raised in the survey and topic of discussion:

An app that can calculate carb to insulin ratios advising on next best steps

### Prioritising patients' unmet needs

The carb/insulin calculator app is of primary use to Type 1 diabetes patients, who need support tailored to them as individuals. The app should provide access to nutritional information for accurate carbohydrate content of common foods, take data on symptoms, treatment and lifestyle and enables secure messaging with doctors and nurses to ask questions.

### Core needs

Already a huge number of diabetes apps exist which carry out basic tracking and recording tasks. The group felt technology now provides the opportunity for better, more personalised interventions – critical in managing Type 1 diabetes. The app therefore needs to move beyond tracking of data to education and coaching so that patients know how to act on that data. Patients need to be able to understand the implications of their data and what to do as a result. However, the group felt that to be properly effective the app must be highly individualised. For instance the same food will have different effects in people according to their context and time the food is eaten. The app can provide education and coaching about actions to take. The support can be provided by an endocrinologist, or specialist in diabetes.

### Barriers to using health apps

Because of the highly individualised demands for self-management of Type 1 diabetes, the medical complexity involved may be beyond a single health app. Health apps that aim to track personal medical data and which are offered on international platforms also often fail to consider the parochial nature of healthcare systems, which use different measures and guidelines in different countries. Because of the potential threat to patient safety, people with diabetes using trackers need some level of medical assurance that the apps are accurate and safe—though the scale of investment to get certification from health authorities could prove prohibitive to the app developer.

Although patients and the public would like to seek advice on issues of treatment and care from their peers via apps, there has been some resistance among app developers to install such a facility as there is a lack of clarity about who is liable if peers provide the wrong advice to the detriment of the recipient of the information. Complexities of legal liability also work against the integration of apps with one another. For example, one company may not take on the risk of another company's app, even where it makes sense to link or integrate them. Finally app developers find it very difficult to reach and involve the stakeholders in apps' testing and development, especially patients, health authorities, regulators, healthcare payers, specialists, and pharma/medtech companies.

### Critical success factors identified

Successful diabetes health apps ought to draw on all the specific skills available in the field of diabetes, from endocrinologists, to nutritionists, specialist diabetes nurses and diabetes educators. Materials need to be co-created between patients, healthcare professionals and developers. Given the technical possibilities, diabetes health apps could do more to offer predictive and personalised support. To progress, though, the regulation of apps needs to be modernised in light of new health app technology. The group also felt that a first important step would be the engagement from healthcare professionals, who need to endorse and realise the importance of patient self-management.





## Disability/pain

**The challenge raised in the survey and topic of discussion:**

**An app that provides a support package for pain management – improving upon what is already available**

### Prioritising patients' unmet needs

The group prioritised a shortlist of essential features of the new app to track pain. The consensus was that there is a real need for an effective pain app diary. The app could, however, also help the patient identify trends from the data they have recorded and what this means for them. In such circumstances, the diary/tracker would need to distinguish between common environmental triggers that set off their pain, such as moving from a hot to a cold room; and pain associated with an underlying medical condition. Such distinctions would enable patients to act so they might curb pain or realise that there is little they can do for pain relief because of circumstances. The tool might support adherence to medication. Although medicine usage trackers are common, the unmet need would be customising it to the patients' specific needs and pain control.

### Core needs

For any person suffering from pain, it is important to be able to identify pain trends—to spot the triggers of pain. As chronic pain is often accompanied by fatigue or a loss of memory, it is also important to be able to record and track pain as well as sharing that data with others. Also essential, is for the app to link to any advances in the passive gathering of data, such as through wearable technology, rather than relying on the patient to input data themselves. The device should be voice-controlled to be accessible to people who are in pain and who have impaired dexterity.

### Barriers identified

A key challenge is that pain is very subjective and very much affected by the mood of an individual—so tracking pain needs to be put into the context of the individual's situation and their needs. The language of pain also varies. Some people may call it aches others even itchiness. Tracking pain medication usage is also difficult, because there are many different types of pain medication. If tracking is to lead to alerts—letting the patient know that they might be

about to experience an episode of pain—the alert must be delivered in a way that suits the individual. If alerts, for example, are exclusively delivered by email, the information may be overlooked when the recipient is not an avid email user. Alerts must also form part of an everyday routine, and not cause unnecessary stress to the individual. Liability is again an issue if the alert system proves faulty, especially if individuals design their own alert. Assuming that an effective pain tracker and alert system can be designed, its usefulness to the patient will be limited by the fact there is usually no real interface between the healthcare system infrastructure and patients' apps. There also needs to be proper integration between apps. It should be possible to collate data from multiple apps. Ideally a single app should act as a programme interface. Finally, if a person is relying on an app to help, the app should be effective over a period of years and updated for new technologies and treatment methods. Also to make sure that nothing is lost, data needs to be easily transferable when the patient moves on to a new device or platform.

### Critical success factors identified

The group agreed there needs to be a significant culture change within healthcare systems to overcome the primary barrier of connecting patients' apps with doctors' systems. Moreover, if people are providing their data to their doctors, they want to see how they benefit from sharing their data, know what will happen to their data, have clear options about opting in, opting out, and sharing some parts of their data, but not others. If possible, both patients and doctors alike should benefit from new mobile technologies. There is an opportunity to build more meaningful partnerships, with well-governed app projects. But the experience of patient groups (and patients) to date has not been a good one. Patient groups involved with pain that have been approached to help make apps often do not receive sufficient detail or are given a reason why the app needs developing; do not have their feedback acknowledged or taken into account; do not feel valued; do not know what happens to any information and comments they provide.



## Mental health

### The challenge raised in the survey and topic of discussion: An app that helps me manage a personal mental health crisis



#### Prioritising patients' unmet needs

The app needs to help a person recognise the type and level of mental health crisis they are experiencing and signpost the person to relevant local support for that type of crisis. The app needs to support people with mental health issues to help them learn how they handle each crisis – what did they learn from the experience, what would they do differently? The app also needs to record any background data relating to the crisis to help identify triggers or length of crisis, support the person to build up their own individual care history, so that they have strategies to call on to help prevent or minimise the impact of a future crisis. An essential element of crisis management would be access to professional contacts to help cope with an emergency. The concept of a 'mental health passport' was floated—to show health professionals in accident and emergency key information—minimising the need for lengthy questioning.

#### Core needs

The group agreed there was space for some generic 'lifeskill' tools for all conditions, focusing on lifestyle and planning tools. However, because mental health management is complex, involving challenging issues such as stigma as well as symptoms of mental illness, apps for mental health/wellness will need to be tailored to specific conditions. Diverse mental health needs also mean that individuals might have to combine apps and other resources over time, building a bank of interrelated tools. Apps for mental health also need to be able to mix and match functionality according to the individual's changing needs, be made relevant to where the person lives. Each app would need to be integrated with any existing care or crisis plan for the person and dovetail with professional support the person is receiving. The app should enable individuals to build virtual networks around themselves – of other service users, peers, family or clinicians. He or she could set up a different network for different types of crises, to get the most appropriate support for their current problem. Information would also need to be supplied to

carers/family/friends on how to help in a crisis situation, at the discretion of the person with mental health issues.

#### Barriers identified

Although mental health crises can have a big cost impact, in terms of ambulance call-outs, or impact on accident and emergency waiting times, the case still needs to be made to healthcare payers that the crisis management apps would save funds by preventing expensive call-outs, minimise time and resources by helping the patient to act before they reach crisis point, or minimise the effect when they do have a crisis. Another tough challenge is convincing people with mental health issues that the apps can be trusted. One step towards that is to ensure that information about funders and developers of the app are made transparent. Users also need to know how the app is validated, and by whom. Aside from the question of trust there is already significant fragmentation in the app market. As a result, current support is too sporadic. Apps need to be aggregated rather than seeing them as acting as multiple stand-alone products.

#### Critical success factors identified

Apps need to be developed alongside people with mental health issues and health professionals at every stage: from testing concept and making sure the app focuses on patients' priorities, to gaining feedback from patients to improve the app once it has gone live. The validation process could be simplified as health professionals could agree on the "essential ingredients" needed in mental health apps rather than looking at individual apps one by one. This would set app developers a clear, clinically-approved model to work to. Another critical factor would be that the user would be in control, giving them flexibility in setting permissions, particularly if he/she does not want family involved in their network or community, and in some cases may see their family as part of the problem. On the other hand the individual user may rely on trusted others to spot their own characteristic, individual warning signs that a crisis is approaching.





## Wellness

The challenge raised in the survey and topic of discussion:

**An app that provides feedback on how treatment, care and lifestyle changes impact my health and wellbeing**

### Prioritising patients' unmet needs

The group defined wellness as “staying as healthy as you can, whether you have a medical condition or not”. For this reason wellness embraces lifestyle factors such as diet, exercise and environmental impact on health. Considering the challenges identified in the survey, the group decided upon three key priorities when designing new apps. First the app should act as a reminder – reminding individuals what to do and when, once lifestyle choices are made. Second, the app should combine a tracker of lifestyle with a log of symptoms and wellness. Third, the app should communicate with healthcare professionals, if the individual wishes to talk about their progress. The app needs to put people's data into context, for example, benchmarking their measures against other patients with similar lifestyle choices, age, risk of specific conditions; explain what the data entered and generated means for the user of the app; understand how the data inform decisions the patient needs to make in order to stay well or get better; and identify when the user of the app may need to contact a healthcare professional or pharmacist.

### Core needs

Attitudes within healthcare are changing to emphasise prevention rather than treatment, though more needs to be done. Health professionals need to help ageing populations to stay healthy longer as well as help people post-treatment to get their lives back on track. Clarification is also required about the whole notion of wellness and its importance, not only to the public but to people with long-term conditions. Standards need to be established by learning from best practices. Support provided should coach people yet be engaging and motivational. Greater networking between individuals helps build a co-operative spirit for improvement, which could be catalysed by the involvement of carers and other third parties to support a health-aware general public aiming to keep healthy. If people link with their peers they can benchmark/compare progress and experience and participate in building and

sharing group data to demonstrate common needs, challenges and solutions.

### Barriers identified

People may not know how to get real value from wellness data. Although many apps today generate data, people are not sure what to do the information. Whatever type of wellness app is developed individuals using them need to be aware of what is healthy and unhealthy behaviour; what is the norm and what is not. As part of this process apps need also to address ‘patients’ as people who are well and want to stay healthy if given adequate support and resources to help prevent their getting a medical condition or from it worsening. At present there is a lack of clarity about who within healthcare should be involved in supporting wellness, and how. Today the initiative is led by insurers, as well as by the individual consumer. However, health professionals should also have a vested interest in community health and wellbeing, although they may be less familiar with receiving wellness data, such as the patient's diet habits, sleep routines, exercise and activity logs.

### Critical success factors identified

Apps should be easy for the patient to use anywhere. Particularly with wellness, it is important to take a long-term view, and track trends. Given that people change their mobile devices on average every two years, it is important that data are not lost. The patient also needs to control which wellness information they share with whom and for what purpose. Moreover, conditions need to be defined about when and where data are to be shared.



# Conclusions and recommendations

The workshop ended in a plenary session with all attendees discussing the results and findings. Much of the conversation reinforced the conclusion reached at the individual therapy roundtables, particularly in regard to the challenges faced by health app developers today: finding and securing funding; getting resources to make apps more accessible for specific disabilities; marketing and raising awareness of apps they have developed; gaining access to health professionals/clinicians for input and validation, and to patients along the development process; and gathering feedback post-launch of the app.

In terms of the subject matter of the day “What do patients and carers need in health apps - but are not getting?” the following points were made at the plenary:

- New ways must be explored to determine the unmet needs of patients from apps, and what will add most value from their perspective.
- A new, more dynamic research methodology is required for digital health apps to improve validation. As one contributor put in, “how can a research process geared up for clinical trials taking a year be relevant for an app that is updated every three weeks?”
- Better, more tailored, and higher profile resources are required to help patients and carers make informed choices about apps. For example, identifying useful apps that are accessible to people with mobility, dexterity, hearing or visual impairments.
- A ‘community’ of health app developers would be useful to share best practice and resources, and collaborate on projects, either building on existing groups like local Health 2.0 chapters, or working with other organisations in different therapy areas, such as mental health.
- App developers need expertise in adapting app for roll-out to other countries, by identifying local partners.
- As health apps are adopted within health care systems it will be important to demonstrate and share best practice of the adoption of technology.

## Conclusions

The feedback from participants was mixed. Some called for greater participation of patients, others that more time was necessary for deliberation, and that a more scientific, credible approach might be called for. Despite engaging discussions no real tangible app will probably emerge from the meeting. As one participant noted, “I think there could be more focus on what tangible thing we aim to achieve as a result of these sessions specifically.”

The stakeholder discussions were also sometimes fraught. One participant wrote, “The aim of the discussion was not clear to me: was it on us to propose what next development should be promoted? Or were there political

issues inside the group? Not clear to me.” One participant complained that patient groups could not represent patients, since they took money from the pharmaceutical industry; another thought the whole subject of self-care and wellness was misunderstood by other participants. As a participant wrote in the feedback form that the discussions on wellness, “were way too broad. As a result, some ideas and suggestions did not fit with my framework.”

However, in some areas the meeting could be declared a success. Greater clarity certainly exists about the general principles which should govern all health apps —including on patient-centred design and improving user trust in apps—though more work is needed on this subject; while extra consideration is clearly needed for apps dedicated to specific therapy area, as described at the roundtables.

This White Paper and the global survey and cross-stakeholder workshop it summarises, are simply early steps on the long, challenging, journey to improve the quality of health apps, in a market flooded with hundreds of thousands of competing apps.

*“Patients and developers need clear guidance to improve the quality of health apps.”*

Is the market for health apps finally showing signs of starting to mature towards a more ideal state where patients and carers can:

- make informed choices about apps?
- select the truly useful quality apps from the many competing for space?

Optimists could say that there are encouraging signs from the fact that in the global survey, patients and carers were able to consider and articulate what they saw as the core unmet needs in their therapy area. With the caveat that those with the greatest experience with healthcare apps are the people most likely to respond, the fact that so many did respond, and so clearly, may suggest that a core group of health app consumers are becoming more experienced, more sophisticated and more discerning.

Pessimists could say that the picture for developers remains bleak, and that the same barriers that have always held them back from creating useful healthcare apps, continue to do so. Worse, the pace and complexity of regulatory and technological change, is coupled with the challenge of getting any ‘airtime’ for an app when the global machine is accelerating and churning out thousands each week. It is a climate that makes getting any health app out, noticed and used appear near impossible, let alone any thoughts of the app paying for itself.

However, within the thousands of healthcare apps, there are some nuggets of good practice, and developers who came to the workshop were demonstrating this. They were not only eager to gain patient and clinical input into their app development process, but it could be fair to say they were at times desperate for this, having had long, aborted and frustrated attempts to bring patients in.



Beyond the hype of the industry's claims about the scale of health app business, the workshop reinforced the view that developers are generally one-man bands or very small companies. In the face of the challenges they need to overcome, it is an uneven battle. The developers at the workshop want to do the right thing. Equally clear from patients is the ongoing frustration and disconnect between what they really need and what developers or clinicians think they need.

We have always believed that meaningful health apps can only happen when proper conversations are enabled between all the stakeholders involved, from developers to patient groups, from clinicians to insurers, from pharma to the technical community and regulators. The survey and the workshop are steps towards making that conversation happen, but much more is needed. Every properly-run hackathon, every piece of proper patient involvement, every cross-functional apps approvals team, is a practical step the industry takes towards best practice.

The workshop invited the converted who already recognise that they need to talk to the other stakeholders. The step change in the industry needs to happen when involving patients throughout from identifying needs through to final testing becomes the norm, rather than an unaffordable luxury. Better to have a few hundred apps that help patients really well, than hundreds of thousands that add little value for anyone.

We very much want this to be an ongoing conversation, and one whatever, your role, whatever your interest, that you will take part in. In five years' time, health apps may not even exist as a distinct medium. However, the principle of embedding digital health solutions around the needs of patients and carers is a fundamental challenge that needs addressing today, even if we are not sure where the technology will take us or what platforms it will run on. Patients have to be in the driving seat, or technology will continue to drive and define app development.

Clearly a tool needs to be developed that enables stakeholders engage and understand user perspectives in a more systematic fashion. For this reason PatientView/myhealthapps.net is resolved, as a next step, to develop a set of guidelines, evolving over time, which will define what patients and carers want from health apps. The first generation of guidelines will be published later in 2015.

## Recommendations

The following recommendations (see next page) draw on the unmet needs expressed by global patients in the survey, and common barriers raised by stakeholders at the workshop including developers, patients, clinicians and the pharma industry. These recommendations aim to explore examples of ways for patients, carers, clinicians and developers to work together to develop high quality apps that help patients and carers self-manage a disease or condition effectively; and to address the practical hurdles developers face, including funding, access to patients and clinicians during development, and technological and regulatory issues and a sustainable business model to finance app updating.



<b>Involve patients</b>	<p>Establish a transparent, fair and sustainable way to involve patients, patient groups and carers in app development, for example:</p> <ul style="list-style-type: none"> <li>■ Develop a patient 'charter' for app development, giving guidance to all stakeholders on how to govern the relationship.</li> <li>■ Develop process charts and checklists to demonstrate different ways to involve patients and carers, and scale involvement up or down according to the constraints of the project.</li> </ul>
<b>Address unmet needs</b>	<p>Identify and address truly unmet patient and public needs, for example:</p> <ul style="list-style-type: none"> <li>■ The market is saturated with 'me too' apps for common conditions like Type 2 Diabetes. Yet, even within this important condition there may remain many unmet needs, such as personalising a patient's support according to the stage of their diabetes journey, the complications they experience and the psychosocial support.</li> <li>■ Switch the balance from information giving and trackers to tools to help patients put that knowledge and data into action and self manage.</li> <li>■ Address the unmet needs within hundreds of rarer conditions.</li> </ul>
<b>Set up a one stop advice shop for developers</b>	<p>Bring together in one place definitive and up to date guidance for developers of healthcare apps on key issues, including:</p> <ul style="list-style-type: none"> <li>■ regulatory requirements.</li> <li>■ clinical approval methods.</li> <li>■ best practice in involving patients.</li> <li>■ horizon-scanning on technological developments, issues and opportunities.</li> </ul>
<b>Share best practice</b>	<p>Identify, develop and communicate models of best practice, for example in:</p> <ul style="list-style-type: none"> <li>■ involving patients and carers in identifying unmet needs.</li> <li>■ building in clinical input and approvals.</li> <li>■ adapting over time to changes in patient needs, clinical standards and technology.</li> </ul>
<b>Gain "air time" for quality apps</b>	<p>Identify ways for developers of quality health apps to market and differentiate themselves from the many available, for example:</p> <ul style="list-style-type: none"> <li>■ offering browsing patient and carers fast ways to find trusted apps.</li> <li>■ patient groups developing and marketing their own apps.</li> <li>■ patient groups identifying useful apps for their own disease/condition.</li> </ul>
<b>Find the business model</b>	<p>Identify sustainable business models for apps, and make this funding transparent to browsing consumers, including:</p> <ul style="list-style-type: none"> <li>■ apps developed by patient groups themselves, as part of their support for members.</li> <li>■ crowdfunding.</li> <li>■ crowdsourcing and other forms of voluntary development.</li> <li>■ subscription models.</li> <li>■ 'free' apps (ad-supported, or with options for paid-for additional functionality).</li> <li>■ 'free' apps with transparent and usable consent for data-sharing.</li> <li>■ pharma, insurer or public health service supported apps.</li> <li>■ find ways to share the financial and regulatory risks across a range of supporters.</li> </ul>
<b>Demonstrate clinical rigour</b>	<p>Clarify clinical approval requirements, for example:</p> <ul style="list-style-type: none"> <li>■ confirm in a definitive and clear way which apps from a regulatory perspective require official clinical approval, for example US FDA, EU, UK MHRA.</li> <li>■ identify how patients can identify the source of clinical input, that it is accurate and up to date.</li> <li>■ build on existing activities which filter apps based on clinical approvals, such as the NHS Health Apps Library, FDA listings, myhealthapps.net</li> <li>■ involve clinicians in demonstrating outcomes achieved by the app, where this is feasible.</li> </ul>
<b>Bring apps into the mainstream</b>	<p>Integrate apps into wider and 'real world' healthcare solutions, rather than remaining fragmentary 'add-ons', for example:</p> <ul style="list-style-type: none"> <li>■ linking to the patient's healthcare record or care team, where the patient wants this.</li> <li>■ linking to supporting websites.</li> <li>■ gaining acceptance from the patient's healthcare professionals.</li> </ul>
<b>Future-proof apps</b>	<p>Making apps sustainable, and adaptable to future changes, for example:</p> <ul style="list-style-type: none"> <li>■ future-proof apps to be transferable across platforms and through software updates.</li> <li>■ support a patient's changing needs on their journey with a long-term condition.</li> </ul>
<b>Enable informed choices</b>	<p>Help patients and carers make informed choices about healthcare apps:</p> <ul style="list-style-type: none"> <li>■ Building on existing sites which list apps reviewed and recommended by patient groups.</li> <li>■ Raising standards of digital/app/ehealth literacy amongst patients, carers and developers.</li> <li>■ Gaining clinician input on recommending/prescribing apps.</li> </ul>

# List of participants

Name	Position	Organization
Andreea Antonovici	Events Coordinator	European Multiple Sclerosis Platform
Louisa Bainbridge	Marketing	Therapy Box
Andrew Banner	Database Manager	PatientView (and Type 2 diabetes patient)
Patrick Bartley	Co-Founder	My Help at Home
Judy Birch	CEO	Pelvic Pain Support Network
Jens Birkenheim	Managing Director	Xperio Health
Rebecca Bright	Director	Therapy Box
Bastien Burlion	Business Developer	dmd Santé
Peta Bush	Designer/maker	Health Wear Designs
Fraser Carlisle	Digital Health Consultant	FleishmanHillard
Emma Clayton	Marketing Manager	Novo Nordisk
Kat Cormack	Client Manager	BuddyApp
Sally Crowe	Director	Crowe Associates Ltd
Fredrik Dehong	Community Relations Lead	mySugr GmbH
Katrina Delargy	CEO and Founder	TIYGA (NI) Ltd
Richard Dijkstra	Director	Belle Media Ltd
Jeanette Drielsma	Senior Manager, European Public Affairs	GSK
Maggie Ellis	Senior Research Fellow	London School of Economics
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Alison Furey	Consultant in Public Health	Southwark Council/CCG
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Jorge Gonzalez	Managing Director	TICBioMed
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Kay Hutchison	Director	Belle Media Ltd
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JJ Sandra Kooij	Psychiatrist/Head	Dutch Expertise Centre Adult AD
Thanos Kosmidis	CEO	Care Across
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Rikke Sønder Larsen	CEO	Samfundsinvestor/Qbes
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Sabine Lobnig	Communications Officer	Mobile Manufacturers Forum

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Judi Mallalieu	Senior Implementation Manager	Janssen Healthcare Innovation
Myriam Martin	Project Manager	TICBioMed
Pauline Morgan	Business Manager	Plas-co
Michael Morgan-Curran	Director of mHealth	Personal Connected Health Alliance (PCHA)
Clive Nead	Editorial Director	PatientView
Henry Nead	Website/Info Point	PatientView
Piet Nelis	COO	Synappz
Tony Newbold	Head of Patient Engagement	PatientView
Marian Nicholson	Director	Herpes Viruses Association & Shingles Support Society
Richcoco Olaribigbe	Entrepreneur	Entrepreneur
Dee O'Sullivan	Director	myhealthapps.net / PatientView
Petr Palan	Director, Strategy & Planning	MSD IT Global Innovation Centre
Mat Phillips	Managing Director	OMP Digital
Ilaria Piuze	Public Affairs & Communication Manager EMEA	Janssen
Kristian Ranta	CEO and Co-Founder	Mendor
Bleddyn Rees	Partner	Wragge Lawrence Graham
Samantha Rushforth	Government Affairs Executive	GSK
Peter Schmidt	Developer	iStayHealthy
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Marc Southern	Head of Digital Health	Fleishman-Hillard
Sarah Strachan	Sales & Marketing Director	Hayward Medical Communications
Emma Thompson	Information and Education	European Lung Foundation
Rob Turpin	Healthcare Market Development Manager	BSI Standards
Erik van der Zijden	CEO	Synappz
Julian Wakeley	Head of Interactive, EMEA and Asia-Pacific	Sudler & Hennessey
David Webber	President	International Self-Care Foundation
Sorayya Webber	Intern	International Self-Care Foundation
Hilda Wieberneit-Tolman	Director	Pijn Platform Nederland
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A free web portal created and maintained by PatientView to provide independent advice to patients, carers and anyone seeking to support and manage their health and wellbeing. All the apps featured have been tried and recommended by patient groups worldwide.

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