



ECPC General Assembly 2016

Brussels, Belgium

3-5 June 2016

mHealth and eHealth: Understanding the future of cancer care

Dee O'Sullivan

Director

myhealthapps.net/PatientView



About PatientView

- UK-based research, consulting and publishing company
- Collects and analyses the viewpoints of thousands of patient groups (and their members) worldwide – since 2000
- Has the capacity to reach out to 120,000 patient organisations worldwide, covering over 1,000 health specialties
- Launched myhealthapps.net in November 2013 to help patients, carers, and health-conscious consumers find apps that have been tried and trusted by people like them



Where we are today...

- Over 450 apps
- Covering **150+ health specialties**
- Apps in **50 languages**
- **Reviews** by over **650 patient organisations worldwide**
- **Transparency**: info on and links to app developer, who funded the app, whether it was developed with a medical adviser, if it has regulatory approval (if necessary)
- **Neutral platform**: only apps tried and recommended by patient, carer or health consumer groups included.
Myhealthapps.net/PatientView takes no money from app developers or app downloads

www.myhealthapps.net

21 apps for cancer:

- Information about particular types of cancer and treatment options
- Prevention advice and lifestyle change support
- Keeping track of and accessing test results, making clinical and other appointments
- Sensors for ostomy bags
- Game to help word recollection and recognition
- Updates on clinical trials
- Participation in research
- Logbooks, diaries to monitor symptoms, pain, daily progression and checklists of questions which can be shared with HCPs, carers, support group

Cancer types:

Bowel • Brain • Breast • Childhood • Head and neck • Lung cancer • Neuroendocrine tumours • Prostate • Rectal • Skin



Reverse the Odds

Languages: English (French, German, Italian and Spanish are also used in the app).

Cost: Free

Developer: Multiplatform team, Maverick TV; Chunk Digital; Zooniverse (Based in UK)
<http://www.mavericktv.co.uk/production/reverse-the-odds>

Support email: apps@channel4.com

Funder: Channel 4 Television, UK

Medical Adviser: Cancer Research UK and the Department of Oncology, University of Oxford, UK

Review: “**Citizen science is all about getting as many people involved as possible**, so don’t worry if you’re not always 100% sure about what cells you can see. Sometimes even researchers disagree. That’s why they have back-up mechanisms in place, and we do, too. Lots of other people will see the same pictures as you, and we have checks in place to spot wayward analysis. The images you’re seeing are magnified samples of real tumour tissue donated by former patients. **By answering simple questions about this data, you’re helping our scientists to learn more about cancer, and more effectively prescribe the most appropriate treatment options for future patients.**”

Cancer Research UK <http://bit.ly/1DmQVpb>



My NET Manager

Languages: English, French

Cost: Free

Developer: Vogel Farina LLC (Based in USA)
http://www.vogelfarina.com/work_1.html ;
Support email: jeff.simmons@novartis.com

Funder: Novartis Oncology, USA

Medical Adviser: Same as funder, and healthcare professionals, and patient advocacy groups

Reviewer: [Carcinoid Cancer Foundation, USA](#)

Review: "The first mobile app for carcinoid cancer and neuroendocrine tumor (NET) patients is available for downloading on the iPhone, iPad, and Android. 'My NET Manager', a free app by Novartis Oncology, offers patients a unique opportunity to track their symptoms, set reminders, access test results, and view important dates. The app includes a medication tracker, an insurance tracker, a place to list physicians' names and contact information, information about NETs, including a glossary, and more. ... A 'Contacts' section offers the app user a place to list laboratories, doctors, pharmacies, and insurance companies."

Source: <http://bit.ly/1ndsoJz>

Patients are increasingly building a repertoire of apps to support their needs

How apps already help people with cancer



UMCG Survivor Care App

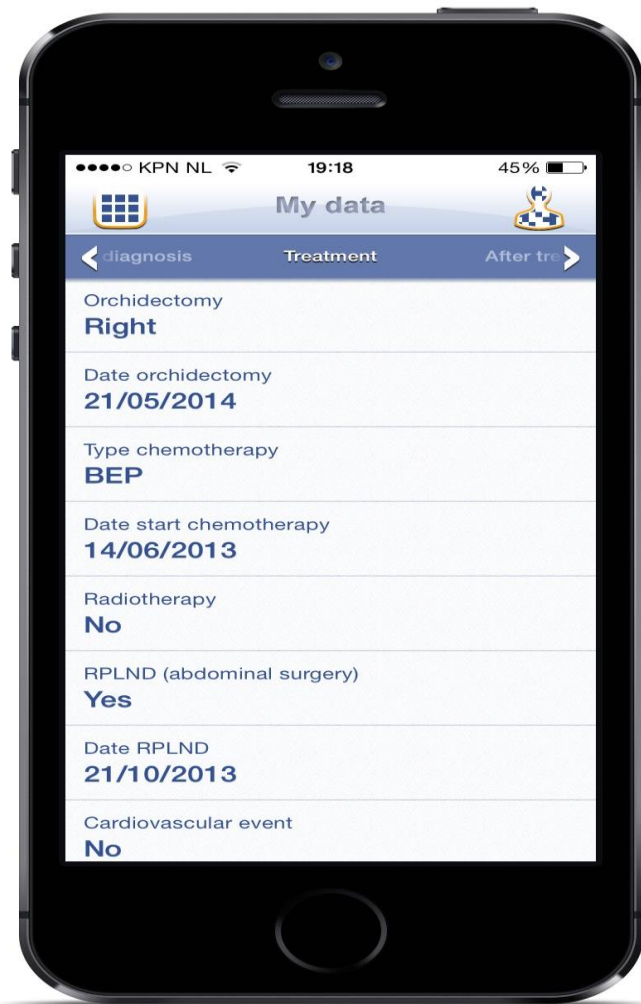
Navigating through Survivorship Care

There is a need to provide cancer survivors and their healthcare providers with a comprehensive survivorship care plan (SCP). The SCP includes a summary of the received treatment and a follow-up plan. This SCP assists cancer survivors and their caregivers to navigate through survivorship phase.

The **Survivor Care App** can read a QR code in which a personalized care plan is encoded. This QR code is generated by the treating physician on this website. The SCP is tailored for the individual survivor of testicular cancer. The app provides survivors with a comprehensive overview of their care plan which allows them to manage to-do's and appointments with their caregivers and set reminders.

The Survivor Care App has been developed by the University Medical Center Groningen in The Netherlands.

The app can be downloaded from the App Store, search for "Survivor Care".



What do patients and carers want from health apps?

A June-Oct 2014 global survey conducted by PatientView, myhealthapps.net, and Health 2.0

- **1,130 respondents**
 - with either a long-lasting illness, or caring for someone who has one
- **From 31 countries**
 - 82.3% from Europe
- 10% with diabetes
- 9.6% with cancer
- 7.6% with arthritis
- 6.6% with a mental health problem
- 6.4% with a rare disease
- 4.9% with a hormonal disorder
- 4.8% with pain
- 4.4% with a heart condition
- 4.2% with multiple sclerosis
- Plus: 39 other conditions

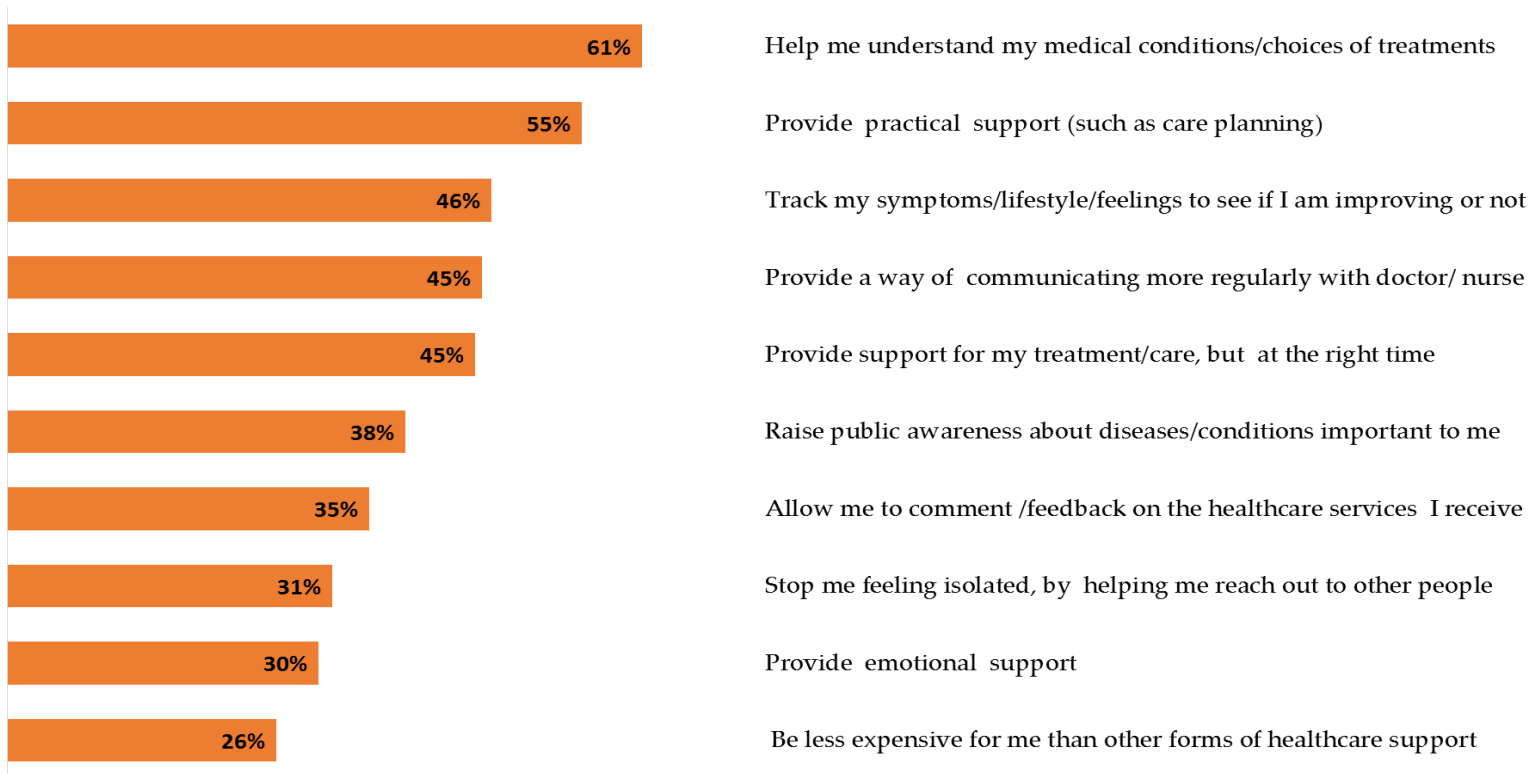
Download white paper with full
research findings from
www.myhealthapps.net/resources

10/11/2014



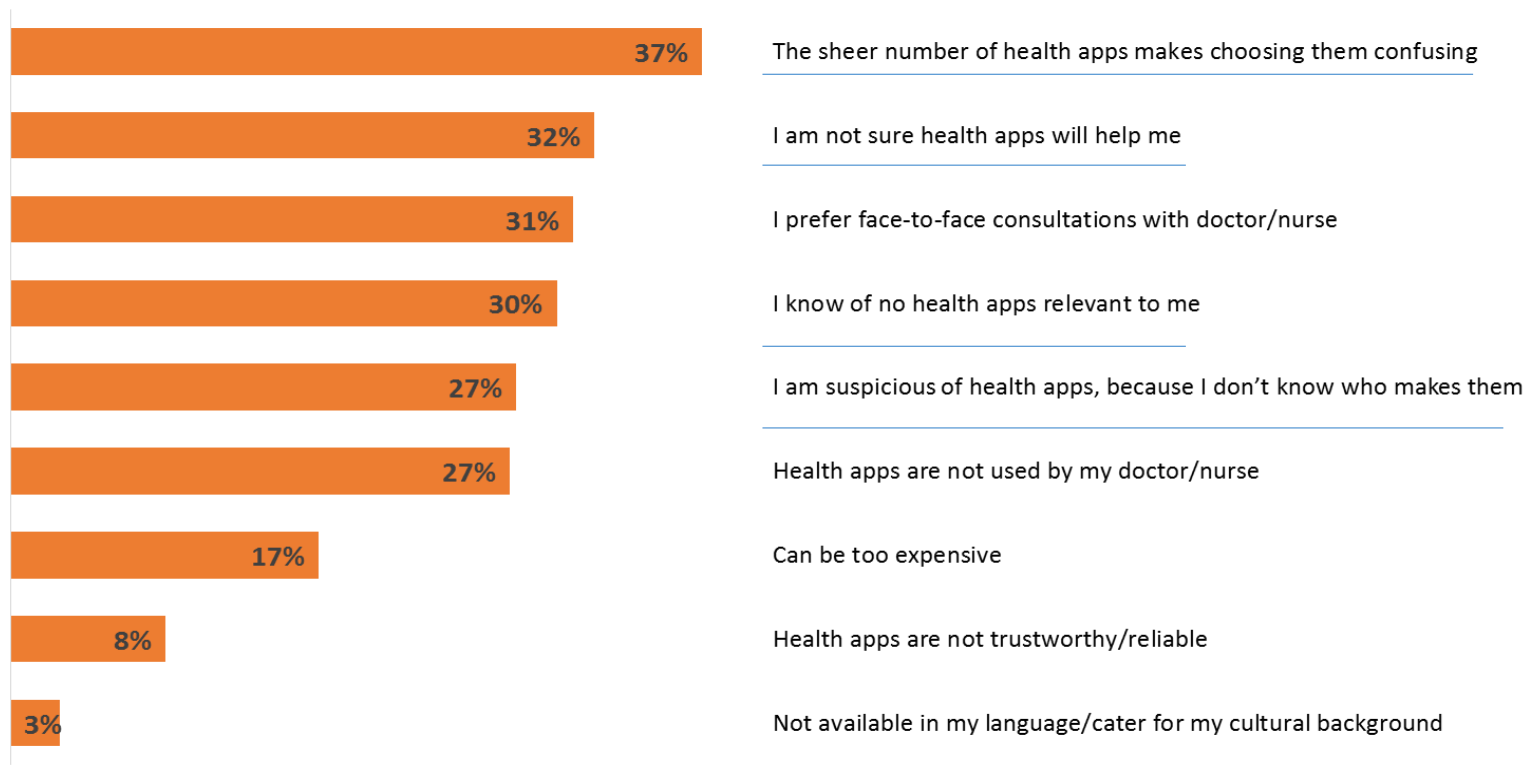
Irrespective of what health apps you are currently using, what do you **want most** from health apps?

But patients aspire to more than information



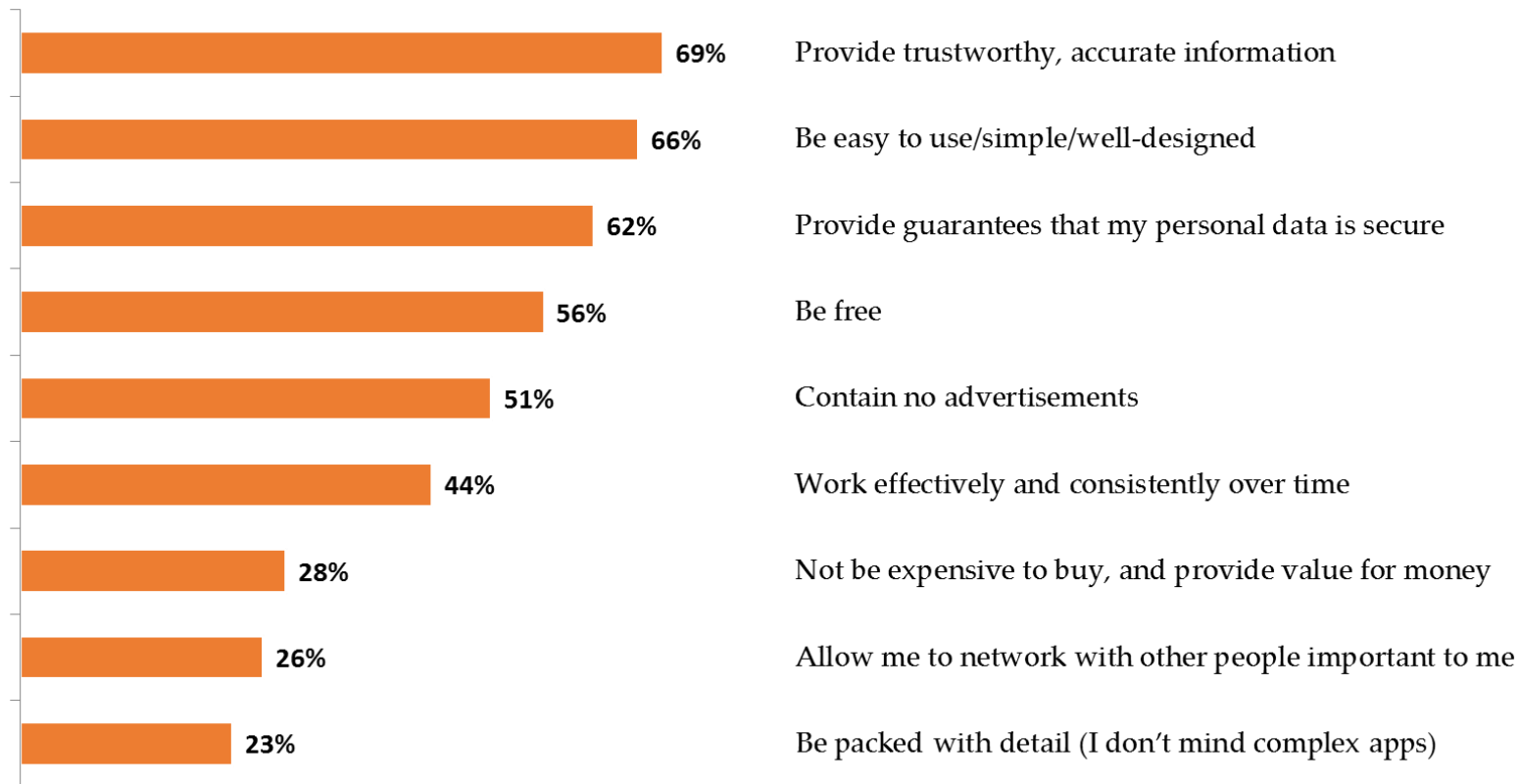
Do any of the following **prevent you** from downloading some health apps, or using them regularly?

Not just about the monetary cost of the health apps ... patients want support on which ones are most relevant to them



*Patients/carers also need
guidance on which apps
to trust*

Which of the following would **convince you** to use health apps regularly?





Cancer

What do respondents involved with cancer want from apps?

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 care
- 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



Cancer

What do respondents involved with cancer want from apps?

Results of survey: general needs

(Respondents were asked quantitative multiple choice questions)

61% want to **understand more about medical conditions and choices** of treatments

46% want **practical support** (such as care planning)

38% want **support at the right time**, such as by issuing me with reminders and other information

33% want **emotional support**

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**

34% want help **to raise public awareness about diseases/conditions important to me**

20% want the app **to be less expensive for me than other forms of healthcare support**



Cancer

What do respondents involved with cancer want from apps?

The specific challenge tackled in the November 2014 workshop

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

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

- **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**

Sustainable healthcare app

FINANCIAL

- Sustainable business model, for example subscription, payer contribution

TECHNOLOGICAL

- Works seamlessly over multiple platforms
- 'Smooth' updates with no loss of data or negative impact on patients

CLINICAL

- Accepted by HCPs and patients because medical content is accurate, and regularly reviewed and updated

INTEGRATED

- Accepted as part of the local healthcare support system
- HCPs, patients and carers clear how this app fits into the person's care

'FOR LIFE'

- Able to adapt and target personalised support for a patient at each stage of a journey with a long-term condition

myhealthapps.net partners and research collaborators





We welcome your input and involvement!

PatientView

Dr Alex Wyke

T: +44 1547 520965

alexwyke@patient-view.com

www.myhealthapps.net

Dee O'Sullivan

M: +44 7497 024897 +32 495 893925

dee@patient-view.com