

Health Companion in Mesothelioma & Lung Cancer

A patient centric
community based patient diary
using validated Patient Reported Outcomes (PROs)

Introduction

We are introducing community based integrated digital health application/service for patients with either lung cancer or mesothelioma in your area. We would like to inform you about it in advance of its introduction, so you can ask any questions – and we can answer or address any concerns you may have.

The following provides the background.

What is the Health Companion?

The Health Companion is an application that allows patients with either lung cancer or mesothelioma to submit data regarding their quality of life, experience of the disease and associated costs. As well as providing useful information for the patient to bring with them to clinic appointments and other healthcare settings, it also allows us to build real evidence on the burden of the disease and provide invaluable insight for new treatments and interventions.

In the future, this information will be linked to a patients' clinical data that is collected by national cancer registries (such England's NCRAS, the Scottish Cancer Registry, The Northern Ireland Cancer Registry and the Welsh Cancer Intelligence and Surveillance Unit (WCISU)). When analysed together the Health Companion and the Cancer Registries provide a comprehensive insight that includes patients' real experiences, and this can be used to review, evaluate and shape the future of cancer treatment and care services.

Who developed the Health Companion?

The Health Companion is a joint project between the charities Mesothelioma UK and Lung Cancer Nurses UK and Dash Global.

Dash Global are a health economics firm who specialise in real world observational research. You can find out more about them here. <https://www.dash-global.com>



Mesothelioma UK is the national charity for anyone affected by mesothelioma. They exist to support patients to live better and to live longer, and to prevent mesothelioma from happening to future generations. You can find out more about them, here: <https://www.mesothelioma.uk.com>

Lung Cancer Nursing UK (LCNUK) is the national charity that supports specialist UK nurses working in the area of lung cancer. The charity is dedicated to the advancement of health by providing nurses who specialise in the treatment of patients with lung cancer or mesothelioma with support, education and the opportunity to communicate and network with peers; and to provide a national voice on clinical and strategic issues for specialist lung cancer nurses. You can find out more about them, here: <https://www.lcnuk.org>

How will patients access it?

Patients will be able to download, register and submit their own clinical data. It can be accessed on a smartphone, desktop, laptop, tablet or iPad.

What information is being collected?

The Health Companion has various sections; some data is collected only once and other sections are to be repeated at intervals depending on patient preference.

Enrolment: On enrolment to the Health Companion, the patient will fill in basic details about their current health situation. The information collected includes NHS number, gender, date of birth, details of diagnosis and treatment and genetic information about their cancer.

Section 1: Setup data including contact details, medical history, clinical history. The full list of questions is available as part of our privacy notice, which is available [here](#).

Section 2: Patient Reported Outcomes. These reports include information about their experiences including symptoms and the impact the cancer is having on their quality of life. These reports take approximately 2 minutes each to complete, and there are 4 of them in total.

Section 3: Experience of Care. This section asks for their experience of the health services in managing their mesothelioma or lung cancer. This typically takes 10 minutes to complete, but only needs to be done at 3 or 6 monthly intervals.

How does it help patients?

The Health Companion is a personal health diary and the information in the app is not connected to the local hospital system and is not intended to provide a link between patients and their care team. However, patients will be able to see their data in easy-to-understand tables and graphs should they so wish. Having talked to patients, we know this feedback can be useful for them to understand and manage their own well-being, as well as being very useful for communicating how they are feeling to family and carers.

What is the role of the nurse specialist?

We do not require the clinical nurse specialists to complete the form or verify the information.

However, what we would like is for the clinical nurse specialist to let patients know this app exists, and to give them an information leaflet with details of how to download and register. The role of the nurse would be only in informing patients of the programme and providing information on how to access it..

We are aware that the trust may have a process to approve promotional materials that are given out by healthcare professionals. We would be happy to provide any information necessary in order to receive that approval. As always, the final decision will be for the clinical nurse specialists themselves, as and when it may be appropriate to introduce the Health Companion App to their patients. We will provide them with an information leaflet on the programme to hand out.

Assurance

The charities have worked with their digital partner:

- to ensure the Health Companion has an ongoing Clinical Safety review (DCB0129) (even though it is a non-interventional tool targeted principally at audit and research);
- to create a Digital Technology Assessment Criteria (DTAC). (The NHSX developed DTAC is a new advisory assessment for the commissioning of digital health technologies. The standard gives staff, patients and citizens confidence that the digital health technologies that they use meet the NHS minimum baseline standards.)
- and have audited their organisations through NHS Digital's Data Security & Protection Toolkit.



Next Steps

Please get in touch by emailing HCmanager@mesothelioma.uk.com or HCmanager@lcnuk.org if you need to ask any questions, are looking for any further assurances or would like to see our promotional materials in advance.

We have already been working with nurses directly over the last two years to inform them of this forthcoming service, which we will be rolling out over the coming 3 months. We will be contacting the nurses to help and inform them and will be supplying the promotional material for their patients.

We hope that you will whole heartedly support this national initiative to both benefit patients and create a more holistic publicly available Patient Reported Outcomes dataset in Mesothelioma and Lung Cancer that we will all have access to and that should lead to better care and better medicines.

Signed on behalf of:

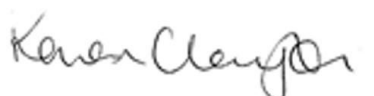
Mesothelioma UK

Signed: 

Name: Faye Forde

Role: Director of Finance and Operations

Lung Cancer Nurses UK

Signed: 

Name: Karen Clayton / Julia McAdam

Role: Chair / Vice Chair for LCNUK

DaSH Global Ltd.

Signed: 

Name: Lee Wemyss

Role: Director