

Patient Enrolment Form

(User Information / Consent / Assessment)

This information leaflet has been put together to help explain: -

1. What the Health Companion is?
2. About the data we collect and how it supports existing national cancer data collection?
3. Who the Health Companion is intended for?
4. Who has developed the Health Companion?
5. Who manages the Health Companion?
6. What information the Health Companion collects?
7. How often users will need to log on and enter information?
8. About the safe storage of Health Companion data and how the data will be used.
9. How is the Health Companion is funded?
10. Common questions and answers.

Once you have read the leaflet, if you are interested in using the Health Companion, please sign the consent form (on page 6) and include your contact email address and mobile phone number and hand the whole document to your Clinical Nurse Specialist to process, who will then add clinical information about your cancer (please see page 9). If you want a copy of the user information to take home with you ask your nurse for a copy. It's all available in the APP or on the web site www.health-companion.me.

Within 5 working days you should receive an email (or text) with your login details and instructions. The Health Companion manager will contact you if you're having problems. The Health Companion manager is available to you throughout, providing information and support.

If you have any further enquiries or require more detail, please contact the Health Companion team via telephone 0116 218 5718 OR email HManager@mesothelioma.uk.com





1. What is the Health Companion?

The Health Companion is a secure, digital information gathering APP which can be accessed via a desktop computer, laptop, tablet, iPad or mobile smartphone.

2. About the data we collect and how it supports existing national cancer data collection

Information about all cancer patients is already routinely collected. In England, this is the job of the National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England. NCRAS collect information about every single cancer patient and use it safely and securely to help doctors and healthcare teams across England. Only by looking at the bigger picture – by collecting data from as many people as possible – can the Cancer Registry teams help doctors decide on the most effective treatment for you.

Scotland, Northern Ireland and Wales have cancer registration services similar to England.

Sadly, the UK still lags behind many other developed countries when it comes to survival rates for cancer. Only by collecting performance data nationally can we drive up standards and improve treatment.

There are many outputs from the data that is collected including NHS England's [Cancer data](#) and [Atlas of variation](#) as well as clinical audits in lung, breast and prostate, national statistics from ONS, and Cancer Alliance and provider performance measures.

The information held is highly sensitive and very personal. For this reason, security and patient confidentiality are at the heart of everything that is done. The NHS have special legal permission to collect patient information without needing a patient's consent.

If you would like to know more about the NCRAS please visit:-

<https://www.ndrs.nhs.uk/national-disease-registration-service/patients/how-data-is-used/>

The Health Companion enables individuals living with lung cancer to provide information about their own experiences of receiving treatment and care. Patients are able enter details about the symptoms they are experiencing, the effects of treatment and about the wider impact the illness is having on their life. This information is then linked to the patient's clinical data that is collected by NCRAS. When analysed together the Health Companion and NCRAS data 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.



3. Who the Health Companion is intended for?

Currently, there are two versions of the Health Companion, one for Mesothelioma and a second one for lung cancer, which is supported by Lung Cancer Nursing UK.

4. Who has developed the Health Companion?

The Health Companions have been developed by a real-world research company called DaSH-Global. DaSH worked with the nursing teams at Mesothelioma UK and committee members of Lung Cancer Nursing UK to prepare the current versions.

5. Who manages the Health Companion?

Both Health Companions are managed day to day by a Project Coordinator and a Manager. A Clinical Expert Panel meets regularly to review the progress of the Health Companions.

6. What information will the Health Companion collect?

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

Section 1: Setup data including contact details, medical history, clinical history etc. Only has to be completed once and takes about 10 minutes.

Section 2: The regular monthly (key data) is called Patient Reported Outcomes - it includes information about your experiences including symptoms and the impact that cancer is having on your quality of life. This is collected in four short (2 minutes each) reports:

Overall Change (a context setting questionnaire),
Cancer Related Quality of Life (FACT-G7),
Lung Cancer Symptom Scale (LCSS - Meso Modification),
General Health Status (EQ5D).

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

Section 4: The financial burden of caring for yourself. By this we mean additional equipment, insurance or private care or support, including any other incidental costs connected with having to cope at home. This is optional. You only use this if you want to record a diary of your expenses and share it. We want this to better understand our patient's financial burden.



7. How often will users need to log on to their Health Companion and enter information?

To start, users will be asked to provide set-up information (this is required only once) followed by an initial set of reports. After this, users are asked to do monthly updates. The Health Companion will remind you. There is also a patient experience questionnaire that you will be asked to complete once or twice a year.

8. About the safe storage of Health Companion data and how the data will be used.

Please be assured, we will carefully protect your privacy at all times. We use the best security and levels of encryption available. We will use the data for audit and research working with Universities, the NHS and Industry to help develop new medicines and improve existing treatments and services you receive.

9. How is the Health Companion funded?

The Health Companions are funded through industry sponsorship and research.

10. Common Q & A's...

i. How long will I be involved with the Health Companion?

That's up to you, but we would like your involvement for between 6 months and a year to ensure we gain an accurate picture from data.

ii. What happens next if I agree to take part?

We will email and/or text message you with a link for you to download the Health Companion and begin participating.

iii. How will being involved with the Health Companion benefit me?

Although there is no direct benefit to your health from taking part in the Health Companion, the information gained will contribute to a better understanding of treatment and care. Also, once you begin reporting, you will be able to see your data in easy-to-understand tables and graphs should you so wish. Having talked to patients, we know this feedback can be useful for you to understand and manage your own well-being, as well as being very useful for communicating how you are feeling to family and carers.

iv. What other choices do I have besides using the Health Companion?

The Health Companion is one of the first digital information gathering platforms developed to collect and understand Patient Reported Outcomes (PRO) with a view to improving cancer care and treatment. Other PRO platforms are starting to appear in many disease areas.



- v. **Will my taking part in the Health Companion be kept confidential?**
Yes it will be kept confidential. Mesothelioma UK, its partners and collaborators take confidentiality of patient data and your trust extremely seriously. We follow strict guidelines as set-out by Government and enforced by bodies such as Public Health England, and NHS Digital who help and audit what we do with your data.
- vi. **Are health professionals able to view the data that I enter into Health Companion?**
Doctors, Clinical Nurses and carers, etc will NOT be able to view your specific, personalised data, unless you choose to share it with them via your phone or tablet summary screens. The Health Companion is a personal health diary first, and an anonymised audit and research platform second.
- vii. **What will happen to my data that is collected through the Health Companion?**
We will use the anonymised data for audit and research working with Universities, the NHS and Industry to help develop new medicines and improve existing treatments and the services you receive.
- viii. **Who should I contact if I have a complaint regarding the Health Companion?**
You should contact the Mesothelioma UK directly. Tel: 0116 218 5718 or email HManager@mesothelioma.uk.com
- ix. **Who should I contact if I have any concerns?**
You should contact Mesothelioma UK directly. Tel: 0116 218 5718 or email HManager@mesothelioma.uk.com
- x. **I am interested in using the Health Companion, what should I do next?**
You should contact Mesothelioma UK directly. Tel: 0116 218 5718 or email HManager@mesothelioma.uk.com





Please complete the following and provide us with your consent...

Enrolling Patient Details:

First Names: _____	Surname: _____
Mobile No: _____	Email: _____
NHS Number / (CHI in Scot.): _____	Postcode: _____
Sex: Male / Female (Please circle or leave)	DoB: ____ / ____ / ____
I plan to use: SmartPhone / Tablet / PC or Mac (Circle one or more)	Request*: <input type="checkbox"/> loan of a tablet

* We only have very limited numbers of tablets we can loan to people who need them and want to take part. Please only tick if you have no smartphone, tablet or PC that you can access at home. (We're sorry that we cannot guarantee loans are available to all who request.)

Patient Consent

Your agreement below confirms you would like to participate in the Health Companion and that you have read the attached information pages detailing how we will use your data.

<input type="checkbox"/> YES	Signature: _____
	Date: ____ / ____ / ____

We may occasionally want to contact you about your use of the Health Companion App. Do you consent to your above details being forwarded to the Health Companion management team so that they can contact you?

<input type="checkbox"/> YES	Signature: _____
	Date: ____ / ____ / ____



Mesothelioma Nurse Completion Form

The following form should be completed IN FULL by the enrolling nurse, *incomplete forms cannot be processed by the HC Manager*, attached to the patient consent form and sent to the Health Companion Manager by freepost envelope. Please email HCManager@mesothelioma.uk.com to inform them that the form has been sent.

Nurse Completed Details (processing the enrolment):

Nurse First Names: _____	Nurse Surname: _____
Nurse ID: _____	Nurse Email: _____
Cancer Alliance: _____	(Name of alliance where patient treated)

Patient details (completed by nurse)

NHS / CHI No. check _____

I've checked it please ensure checked and confirm here

Type of Mesothelioma: (tick one only)	<input type="checkbox"/> Pleural	<input type="checkbox"/> Peritoneal	<input type="checkbox"/> Epithelioid	<input type="checkbox"/> Biphasic	<input type="checkbox"/> Sarcomatoid	
ECOG Perform. Score:	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> Unknown

Where is the patient in their pathway (tick only one of the following)

Newly diagnosed/ On or about to start treatment Newly diagnosed / Not pursuing treatment

Continues on treatment / Maintenance treatment

Stable / On surveillance post treatment (incl. surgery) Stable/ On surveillance – no treatment to date

Relapse / On or about to start treatment Relapse / Not pursuing further treatment (incl. Refractory)



Genetic Subtype Status BAP1 P16 + ve
PD-L1 expression Positive Negative Unknown

Currently on Chemo or Immunotherapy?

Yes No

Maintenance
Therapy?

Yes No DK

Line:

Cycle:

Date Started:

Planned Cycles:

Currently
prescribed:

___/___/___

Was chemo prescribed as part of a clinical trial?

Yes No DK

Surgery: Yes No DK

Radiotherapy: Yes No DK