

Neuro-oncology department

Using questionnaires for brain tumour patients

Information for patients, relatives and carers

Introduction

We want you to know how you will be helping if you take part in these questionnaires.

It will help us provide better care for you. It will also improve the care for future patients with brain tumours.

Please ask your healthcare provider if you have any questions. Thank you for your help and support.

Why are we doing this?

Many patients with brain tumours find it gets harder to carry out daily activities. Currently, we use a score to assess your overall fitness for treatment. But we do not regularly ask how you're managing with everyday tasks.

We have services that can help you. These include physiotherapy and occupational health. But how we decide to send patients to these services is not always the same.

So, we want to use questionnaires to check your daily functioning. This will help us understand if this approach is better than what we do now. It could also help us refer you to support services more quickly. This could reduce hospital visits and emergencies.

What it involves

- **frequency:** we'll ask you to fill out a questionnaire once a month
- **format:** you can receive the questionnaire by email or on paper during your clinic visit.
- **types of questionnaires:** we will use the following:
 - Amsterdam IADL Questionnaire – UK Version (A-IADL-Q-UK)
 - Functional Assessment of Cancer Therapy – Brain (FACT-Br)
 - European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)
 - Barthel Index of Activities of Daily living

How it could benefit you

- **clinic discussions:** we can talk about your questionnaire scores during your clinic visits to better understand how you're doing
- **personalised care:** regularly checking your daily functioning helps us make better decisions about your care. This includes timely referrals to physiotherapy or other support services

What it can help us understand in the future

- **better tools:** we want to see if these questionnaires help us identify when patients need more support
- **improved referrals:** consistent checks may help us refer you to the right services more quickly
- **enhanced care:** our goal is to improve your quality of life and reduce hospital visits by catching issues early

Confidentiality and your rights

- **confidentiality:** all the information you provide will be kept confidential. Only authorised healthcare professionals will have access to your responses
- **opt-out:** participation is entirely voluntary. You can choose not to take part or stop taking part at any time. This will not affect your care

Thank you

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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