

Age UK Integrated Care Programme Information Protocol

Fair Processing Notice

Age UK's Personalised Integrated Care Programme have agreed to share some basic information about individuals who have used the programme to see how well our service works in reducing the need for hospital care. We hope that through studying your records and those of others we can make this service better for others in future. This fair processing notice is relevant to people who have used the scheme in Portsmouth, North Tyneside, Ashford and Canterbury, East Lancashire, Blackburn with Darwen, Sheffield, Guildford and Waverley, and consented to data sharing.

The first principle of the Data Protection Act 1998 requires that personal data is processed fairly. To meet this requirement these organisations are under a duty to supply you with a Fair Processing Notice.

In a sharing context, a Fair Processing Notice should at least tell a data subject:

- The identity of the organisation who controls the data you are sharing
- The reason it is being shared
- The agencies that your information is likely to be shared with

The organisation controlling the data that you have supplied is your local Age UK organisation.

Personal data is being shared in order to see if this service leads to a reduction in people's need for hospital care.

NHS Digital is the only agency that your personal information will be shared with. NHS Digital will then remove any personal information that says who you are and share the anonymised information with the Nuffield Trust, so that it can carry out the evaluation. The research team at the Nuffield Trust will not be able to identify you personally.

All members of staff employed by these agencies are bound by the common law duty of confidentiality which means that information that you provide to us must be held in confidence and not shared with anyone else unless:

- Partners are legally obliged or permitted to disclose the information to another organisation or person
- You/your carer provide consent to share the information

Please read the information in the table below which gives details of what we have proposed for the evaluation of this programme.

Question	Answer
Why do you want to share information about me?	We want to see how well our service works in reducing the need for hospital care. The Nuffield Trust is undertaking an evaluation of this service to see if it leads to a reduction in people's need for hospital care. In order to do this evaluation, we want to be able to share some basic information about you with NHS Digital, which collects information about all hospital treatment in England, and the Nuffield Trust, who will undertake the evaluation.
Who will be using my information?	1) NHS Digital – a part of the NHS in England 2) The Nuffield Trust, a reputable independent research organisation, will subsequently analyse anonymised information.
What information will be shared?	Your name, address, NHS number, sex, date of birth and a unique study number (assigned to you by this service) will be transferred securely from Age UK to NHS Digital. NHS Digital will then remove any information that says who you are and share the anonymised information with the Nuffield Trust, so that it can carry out the evaluation. The research team at the Nuffield Trust will not be able to identify you personally.
How much information will you share?	For this evaluation, the information given to NHS Digital will only be enough to show whether the NHS Digital holds any records of whether you have used a hospital.
What happens after my data is shared?	NHS Digital hold information on all hospital attendances in England and they will be able to identify if they have any electronic records about you. They will then be able to extract information about whether you needed hospital care after receiving our services. This information will have anything that identifies you removed and will then be sent to the Nuffield Trust. The findings from this study will be presented in a report to be made available on the Nuffield Trust's website. No information about individuals will be published.
How long will my data be stored?	NHS Digital will destroy any information they receive from us once they have found if you needed to be seen by the hospital and sent that information (without anything that could identify you), to the Nuffield Trust. The information held by Nuffield Trust will be destroyed three years after publication of the final reports. If you would like more information on this see http://www.nuffieldtrust.org.uk/
Will my data be looked after safely?	Yes. Your information will be sent securely to the NHS Digital, which works under strict rules to keep your information confidential. Information on the NHS Digital is here: http://content.digital.nhs.uk/article/3768/For-the-public . Information about The Nuffield Trust is here http://www.nuffieldtrust.org.uk
What are the potential risks for me?	The risks are that people working at the NHS Digital may be able to identify that you have received this service. Please note the NHS Digital already handles large quantities of confidential information as a national 'safe haven' for health data. The Nuffield Trust researchers will not be able to identify you personally and will not share your information with external third parties.
What if I do not want to consent to sharing my information or change my mind?	You do not have to agree to sharing information if you do not want to. If have agreed, you are free to withdraw at any time, without giving a reason. You can notify us and your records will be excluded from the evaluation. Whether you consent or not to sharing your information, this will not affect the support you receive.
What happens if I have a question, concern or complaint?	If you have any question about the evaluation of this service or concerns about the way it has been carried out, you should contact in the first instance your local Age UK organisation. If you are unhappy about any aspect of the evaluation or wish to complain formally, you can do this in first instance directly to the Chair of Trustees of the Nuffield Trust, Andy McKeon (59 New Cavendish St, London W1G 7LP), or to the Charities Commission (https://www.gov.uk/government/organisations/charity-commission). Any complaints about NHS Digital should be to their Contact Centre Contact Centre at 0300 303 5678 or enquiries@nhsdigital.nhs.uk

Under the Data Protection Act 1998 you have the right to request a copy of your information (for which a fee of £10 may be charged).