

PARTICIPANT INFORMATION LEAFLET (SERVICE USERS)

“Implementing myGRaCE in primary care and the community”

INVITATION TO TAKE PART IN OUR RESEARCH STUDY

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Please ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this

What is the purpose of this study? The purpose is to enhance the safety **and wellbeing** of people with mental health problems in the community. Our aim is to help people have a better understanding of the kinds of risks they may face and the factors in their lives which can affect **both their safety and wellbeing**, so that they can monitor themselves and be better able to self-manage **in the community**.

We have developed a new online self-assessment tool for service users, called myGRaCE. This has been developed with mental health service users and is a companion to clinical versions of the Galatean Risk and Safety Tool (GRiST, www.egrist.org). It allows service users to collect the same information as clinicians do, but with a more suitable interface and language, and with more emphasis on wellbeing **as well as** safety.

The idea is that myGRaCE should help service users and clinicians talk about what makes people feel safe and what puts them at risk of harming themselves or others, and to understand each others' point of view. This should support partnership working in assessing and making decisions together about how best to manage personal safety **and wellbeing** in the community. myGRaCE also provides service users with feedback about the level of risk in their lives, along with links to self-help resources and advice about self-management planning.

We have not tested out the usefulness of myGRaCE in secondary care mental health services before.

Why have I been invited? We have invited you because you are currently receiving support for a mental health problem from secondary care mental health services, and because your clinician thinks you are the right kind of person to help with this study. You have first hand experience of being on the receiving end of clinical risk assessment and are **preparing to manage your own safety in the community**. Your clinician thinks that using myGRaCE would be helpful for you.

We want myGRaCE to be as useful as possible to people with mental health problems, and so we are asking you to test it and to tell us about your experiences of using it in practice. We need to know if it has all the functionality you need, and if it is presented in the right way for you. We also want to know if and how you think it might help you to assess and detect risk, and to monitor and manage it at home. We are also interested in how myGRaCE affects your ability to work in partnership with your clinician.

Do I have to take part? No. It is up to you to decide whether or not to take part and even if you do decide to, you are free to withdraw at any time without giving us a reason.

What will happen if I take part? We would like you to try out using myGRaCE, **preferably** in preparation for any meetings with your clinicians, **but** it is entirely up to you what myGRaCE information you share with them. We would also like you to fill in a brief on-line survey about your

experiences of using myGRaCE. **Your feedback will help us to improve myGRaCE so that many more service users like yourself can benefit from it in the future.**

If you find myGRaCE helpful, you can carry on using it as often as you like in your own time. You can also send us feedback via the survey as often as you like. The more feedback we get, the more we can improve myGRaCE.

Your clinician will tell you about the study and **a member of the research team will talk through this information sheet with you. A copy of this information sheet will also be available online and you can ask the research team further questions too. A research team member will demonstrate myGRaCE to you and give you details about how to login to the myGRaCE website and how to give consent to take part online.** If you do decide you would like to take part, **they will help you to open your own account so that you can just login and follow the instructions there.** You will be asked to fill in an on-line consent form before being directed to myGRaCE.

From time to time you will receive emails from myGRaCE. They are designed to help and encourage you, by reminding you about how to use myGRaCE and how to give feedback, for example. You can unsubscribe from receiving these at any time if you wish.

What do I have to do? First, we would like you to take some time to think about whether you would be willing to take part in the study. Take as much time as you need to decide and talk it over with your family or your clinician, or with a member of the research team. If you decide not to take part, you will not be contacted again about this study.

Once you have started to use myGRaCE, the website will let you share your self-assessments with your clinician, so that they have a better understanding of your situation from your perspective. This is entirely up to you though. You are free to decline to share your self-assessments without having to give a reason, and without it affecting either your use of myGRaCE or your care. All you have to do is untick the box for sharing.

What are the possible benefits of taking part? The main benefit is that the research will result in an important new self-help resource for people in the community with mental health problems, which will help to keep them safe. Other potential benefits are:

1. improving your knowledge about risk and how best to reduce and self-manage it, to promote your wellbeing;
2. helping to shape myGRaCE so that it meets the needs of people in the community with mental health problems and their families and carers;
3. learning to assess, detect and develop ideas about self-managing any risks you may face at an early stage, with the help of your family and carers;
4. improved risk communication between you and your family, partner or carer; and between you and your clinicians;
5. better partnership working between you and your clinicians around risk assessment and management;
6. improved confidence in your own ability to self-manage your personal safety and wellbeing.

Are there any disadvantages to taking part in this research? We do not anticipate any disadvantages, aside from the need to invest some time to become familiar with using myGRaCE at the beginning, and filling in the on-line survey. The survey will only take 10 minutes to complete.

Will my involvement in this study be kept confidential? All information collected in myGRaCE and during the survey will be kept strictly confidential. Our procedures for handling, processing, storage and destruction of the data comply with the Data Protection Act 1998. This means that information about your contact details will be kept in a secure location separate from the information collected in myGRaCE and as part of the survey.

All survey and myGRaCE data will be stored electronically in an anonymous form on the secure server at Aston University. A code number will be used for reference and not your name or anything that could identify you. Only members of the research team will have access to the survey and myGRaCE information collected. You may choose to allow your clinician access to some of the myGRaCE information you collect, but this is entirely up to you. You will be able to indicate your wishes about this on-line. We will not use individually identifiable material in any of the reports we produce about the project.

In line with **Aston University** data storage policies, any survey data will be kept for a period of 5 years after the end of the research project, after which they will be destroyed. Personal information will be discarded as soon as the project is finished and the findings reported.

We have NHS Research Ethics Committee permission to analyse information stored in the myGRaCE database in an on-going way. This is to help us answer important research questions about risk, safety and wellbeing in mental health, the results of which will benefit everyone. Again, please be assured that research findings will be completely anonymous. No one will be able to link your details to any information in the database or to any specific research findings. This is because all personal details are stored on a completely separate secure server from the one with the anonymous myGRaCE data.

What will happen if I don't want to carry on with the study? If you decide you don't want to carry on with the study you may withdraw at any time without giving a reason and without consequence.

What happens if I have any concerns? If you have any concerns about anything to do with this study, you should speak to the research team and they will do their best to address them. Contact details can be found at the end of this information sheet. If they cannot help you and you still have concerns or wish to make a complaint about the way in which the study has been conducted, then you should contact the Aston University Director of Governance, Mr John Walter, at j.g.walter@aston.ac.uk or telephone 0121 204 4665.

Alternatively, you can contact The Patient Advice & Liaison Service (PALS), which deals with queries and concerns from patients, relatives or carers regarding their health care, and can provide information on NHS services generally.

Telephone: 0800 212 445 or 02476 536804

Email: pals.complaints@covwarkpt.nhs.uk

Please visit the Trust website for further information: www.covwarkpt.nhs.uk

What will happen to the results of the research? The results will be used to help us improve the functionality and presentation of myGRaCE, and to develop guidance for people on how best to use it, including about partnership working with clinicians. We will write a report for our funders and a feedback document for yourself and other service users who have taken part in the research, and one for participating clinicians. We also plan to publish our findings in peer-reviewed journals.

Who is funding the research? The study has been funded by the Judi Meadows Memorial Fund, and it is now partly funded by the EIT Health European Union research programme.

Who is providing sponsorship and professional indemnity for the study? Sponsorship and professional indemnity are provided by **Aston University, Birmingham B7 4ET.**

Who has reviewed the study? This study has been reviewed by the trustees of the Judi Meadows Memorial Fund and by a panel of academic experts in the field of mental health risk assessment and service user representatives. It has also been reviewed by the National Research Ethics (NRES) Committee West Midlands - Solihull.

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Implementing myGRiST (now myGRaCE) in primary care and the community

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Thank you very much for considering taking part in this study

