SAMARITANS' RESEARCH ETHICS POLICY

This policy applies to all Samaritans staff and volunteers who are involved in commissioning or conducting research projects on behalf of Samaritans. In addition, any external researchers or research students who are being supported or commissioned by Samaritans to carry out research must also adhere to this policy.

Samaritans attaches considerable importance to the maintenance of high ethical standards and best practice in all research projects conducted by Samaritans staff and volunteers, or on behalf of the organisation by external research agencies and consultants. For this reason, any work which involves contacting vulnerable people, current or past callers, volunteers and members of the general public requires due consideration with regard to ethical best practice and data protection legislation.

For the purposes of this policy, the term 'research' is used to represent research and evaluation projects that are carried out in traditional research settings, and through Internet Mediated Research (IMR). For specific issues related only to IMR see section 11.

1. Application of the policy

1.1. Research that involves contacting and collating information from current or past callers, volunteers and members of the general public and is carried out by;
- 1.1.1. Samaritans staff or volunteers
- 1.1.2. External research teams that are supported or commissioned by Samaritans to carry out research on their behalf

1.2. Monitoring of activity and operations carried out by staff and volunteers must adhere to Samaritans Confidentiality Policy (see Appendix 1) and Data Protection Policy, but does not have to adhere to this Research Ethics policy, as this is not classified as research. Included under this heading are (for example):
- 1.2.1. Operational caller support and management information
- 1.2.2. Branch data collection and statistics
- 1.2.3. Monitoring requested for specific projects.

2. Ensuring the well-being of participants

2.1. The physical, social and psychological well-being of participants must not be adversely affected by participating in research.

2.2. All participants must be able to understand any information provided so that they can make an informed choice about participation. Participants must be emotionally robust, and examples are:

2.2.1. The participant must not be at risk of being adversely affected by participating in the research and 'telling their story'. Participants must be able to reflect on their experiences and tell their story without this resulting in significant distress. If there is a risk of distress to the participant due to the nature of the research and how it is being conducted, then sufficient precautions should be taken to minimise this risk.

2.2.2. The motivations of participants for taking part in the research are varied but may include wanting to tell their story and contribute to the research process. However, participants should be advised that research is distinct from therapy and should be dissuaded from using the research process as if it were therapy. Participants should not be in crisis at the time of participation.

2.2.3. Participants should be made aware of the levels of confidentiality and anonymity related to the project. For example, if a participant agrees to be a media case study, they must be aware of what that means in practice and the wider implications of being in the media, such as a reduction in privacy and possible stigmatisation.

2.3. Participants must receive information about appropriate support organisations they can use if they experience distress during or after taking part in research, especially where the researcher is concerned about their well-being.

3. Informed consent

3.1. Participants must be fully informed about the project before agreeing to take part. The information should be written and presented in an accessible format, enabling participants to be fully aware of what is expected of them, the amount of time they will have to commit and any potential negative or distressing outcomes.

3.2. Participants must be aware that it is their choice whether they take part, and must not feel pressured to participate.

3.3. Participants must be aware that they can withdraw at any stage, without needing to give a reason.

3.4. Participants must provide written consent that they agree to take part in the research. For consent issues via Internet Mediated Research (IMR) see section 11.

3.5. If the research sample comprises of participants who are aged under 16 years, the parents/carers of the participants should be fully informed and provide written consent for their child to take part. Individual written consent

of the young person is also required. Exceptions may arise where, for example, a school may act in *loco parentis* and provide written permission for all pupils to participate.

4. Confidentiality and anonymity

4.1. Participants must be fully informed about the level of confidentiality and anonymity possible for the project. A full explanation of what this means in practice should be given.

4.2. Confidential information can only be passed on to relevant parties if required or justified by law, or where the participant has disclosed a risk of immediate serious harm (see section 7).

5. Use and dissemination of information

5.1. Participants must be fully informed that the information they provide is for the purposes of the research only, and how the information will be used, e.g. publications, training events, campaign materials, and whether they will be identifiable.

5.2. Participants will be informed about the types of feedback they can receive on the findings of the research. All participants who request feedback must receive it.

5.3. Researchers should fully report research procedures, results, and analysis methods accurately and in sufficient detail so that they are accessible to readers and can be replicated.

5.4. Publications from the project must maintain the confidentiality and anonymity of all participants, except in cases where participants have granted permission for their identity to be disclosed and where disclosure is in the interests of the research.

5.5. Acknowledgement of those involved in the project can be given as appropriate, e.g. external research teams, staff and volunteers. If anyone involved in the project is named and therefore identified in the acknowledgements, agreement is required beforehand. All papers or publications used to inform the project must be suitably referenced.

5.6. Disseminated information must not be false or misleading. For example, branches must not pass off findings generated from local-based projects as if they are representative of, or relevant to, Samaritans as a whole.

6. Data protection

6.1. All electronic data collected during the research must be stored securely in password-protected files. Hardcopy materials containing personal or sensitive information must be secured in a locked cabinet. Research data should only be accessible to designated researchers and for the purposes of the research.

6.2. Only information that is relevant to the purposes of the project, or required by law, should be collected and stored.

6.3. Data should only be kept for as long as they are of benefit to the project, or in the interest of participants. Data that are no longer required should be appropriately deleted or destroyed.

6.4. Where appropriate, a data processing agreement must be in place with any external research teams that are supported or commissioned by Samaritans to carry out research on their behalf.

7. Disclosure of risk of 'immediate serious harm'

7.1. 'Immediate serious harm' must be clearly defined for each research project so that the definition can be provided to the participant and any disclosure is managed appropriately.

7.2. Participants must be informed that, if they disclose that they or someone else is at risk of immediate serious harm, this information will not remain confidential. (This approach differs from Samaritans Confidentiality Policy: research is not a process of emotional support).

7.3. Participants who disclose they or someone else are at risk of immediate serious harm will be offered support either by Samaritans or referred to another organisation. The nature and specifics of support offered must be determined by the researcher and based on the disclosure made and the specifics of the research project (see appendix 3).

7.4. Where a disclosure of immediate serious harm is made by a participant, the researcher must inform the participant what the next steps will be, and whether the disclosure will be referred to a third party. Ideally consent should be sought from the participant before any information is passed on to a third party. The researcher must also inform their manager and discuss the most appropriate way to manage the disclosure (see appendix 3).

8. Expenses and Payments

8.1. Participants should receive reimbursement for reasonable expenses incurred during the course of a research project, e.g. travel expenses.

8.2. A decision to provide payments for participation, and how much, will depend on funds available.

8.3. The researcher responsible for the project needs to assess whether it is acceptable to pay participants for their time and contribution to the research, and any implications this may have on recruitment.

8.4. It may be appropriate to use an incentive to take part in research, such as an entry into a prize draw, or reward an organisation for their help with the research, e.g. resources for an organisation's library.

8.5. Researchers must not accept gifts (in money or in kind) from funders, participants or stakeholders, as this can undermine impartiality.

9. Researcher Conduct

9.1 Evidence, data, findings or conclusions from the project must never be fabricated, falsified or misrepresented.

9.2 Researchers should act in such a way that they do not jeopardise future research opportunities, the public standing of the field or the reputation of Samaritans.

10. Complaints

10.1 Research participants will be informed about the complaints process. A participant who has concerns or a complaint should contact the researcher responsible for the project. Contact details for the researcher should be provided to the participant on a resource, such as the Participant Information Sheet.

10.2 A researcher who receives a complaint from a participant must discuss this with the Head of Policy and Research at Samaritans General Office.

10.3 A research participant who has a complaint about the researcher responsible for the project should be referred to the Head of Policy and Research at Samaritans General Office.

10.4 Complaints by members of the general public about Samaritans research projects should be referred to Head of Policy and Research at Samaritans General Office.

10.5 Complaints by funders should be directed in the first instance to the Head of Policy and Research at Samaritans General Office. If additional input is needed, this must be referred to the Executive Director of Policy, Research and Development at Samaritans General Office.

10.6 Details of the complainant and the complaint will be recorded, additional information sought if necessary, and a response made by either the Head of Policy and Research or the Executive Director of Policy, Research and Development at Samaritans General Office.

11. Internet Mediated Research (IMR)

11.1 Though most elements of research ethics apply to all research, IMR projects may require special consideration by ethics committees. This must be done on a project by project basis.

11.2 Researchers must determine whether IMR is a suitable approach for the purposes of the research and for the sample population being studied. One limitation of IMR is that the researcher has less control than in conventional research over who takes part and in what kind of environment.

11.3 When recruiting participants for IMR through email, researchers need to consider any risk due to the use of non-secure emails and legislation regarding unsolicited 'spam' emails.

11.4 For observational studies (e.g. observing behaviour and use of chat rooms) researchers must consider participants' expectations of privacy, whether observing is intrusive, and whether using these data could cause harm to participants who are not aware that their online behaviour is being observed.

11.5 Researchers need to consider risk to confidentiality, as it is not possible to guarantee absolute confidentiality to IMR participants (the researcher cannot control the networks). For example, email content may be stored by web hosting companies.

11.6 Researchers need to inform IMR participants how the data they provide is electronically stored and transported. Additionally, if participants post any information online for the purposes of the research, they must be informed that this could be seen by the public via search engines. Unless a participant has provided consent, researchers need to consider how reporting any data obtained from the internet could pose a threat to a participant's privacy, e.g. using a participant quote that could be traced through a search engine.

11.7 Anonymity must be applied to a website address, discussion forum, and pseudonyms used by participants.

11.8 Researchers need to consider whether IMR is suitable for participants who require permission from a parent/carer to participate, e.g. those aged under 16 years. This will depend on the nature of the research and the complexity of gaining dual consent from both the participant and the parent/carer.

11.9 Researchers must provide a simple and accessible information sheet and consent form at the beginning of IMR that will increase the likelihood of participants' reading it and providing 'informed' consent.

11.10 Researchers must ensure withdrawal from research is clear to participants, e.g. by providing the researchers' contact details, issuing ID codes to enable data to be identified and withdrawn, or providing participants with a cut-off date where all data will be anonymised and therefore untraceable.

11.11 Researchers must provide IMR participants with a debrief page to ensure they are clear on key issues and where they can access support, if required. Researchers should consider how participants who drop out of the research can receive a debrief page and how accessible they are to respond to communications from participants.

11.12 Researchers need to consider how they will provide feedback and disseminate the research findings to IMR participants. Information on how participants can request or access feedback must be provided.

11.13 IMR that involves observing, for example, discussion forums and chat rooms must consider the levels of deception and provide justification for this approach in relation to the research question and aims.

11.14 Researchers who use any sensitive materials that could cause significant distress to participants are advised not to use IMR. Since the researcher does not have physical contact with participants s/he is unable to intervene and provide support to participants when needed.

11.15 Researchers must inform participants about the research in a clear and accessible format. Participants must be informed about how long their participation will take and any costs incurred for those using 'dial up' internet access.

11.16 Researchers carrying out IMR must ensure that their professional and personal online boundaries are maintained. For example, researchers are advised to only use work emails and not use any personal types of online contact.

11.17 Samaritans and external research teams that are supported or commissioned by Samaritans to carry out research on their behalf are responsible to notify the ICO that it processed personal data for the research purposes.

12. Process and Organisational Matters

12.1 All Samaritans research applications and projects are considered by the Research Team at Samaritans General Office to ensure they adhere to the Research Ethics Policy and will not put the organisation at any risk.

12.2 Where a project is being designed internally by the Samaritans Research Team in General Office, the research proposal and plan must contain a section on ethics, which clearly sets out how the project meets the requirements of this policy. This must be approved by the Policy and Research Steering Group, which is chaired by the Executive Director for Policy, Research and Development and includes (at least) one member of Samaritans Board of Trustees, with sufficient standing and research expertise to provide guidance and oversight of research activity and ethics.

12.3 Samaritans branches must ensure that any external research projects they commission, support or undertake are carried out ethically and adhere to this policy. They must obtain written confirmation from the Senior Research and Evaluation Manager at General Office that the research does adhere to this policy.

12.4 All Samaritans researchers are subject to checks by the Criminal Records Bureau.

12.5 Samaritans is committed to ensuring the personal safety of researchers. It will encourage the use of mobile phones and identity cards, and the use of a monitoring system for checking researcher whereabouts and activities.

12.6 A full copy of the ethics policy must be issued to external agencies (including research institutions, universities and market research companies) undertaking commissioned research on behalf of Samaritans, prior to the commencement of work. External agencies must also have their own ethics policy and these should be reviewed by Samaritans prior to contract. External institutions or organisations with an Ethics Committee must produce evidence of ethical approval.

12.7 Adherence to the ethics policy will be required as a key component of the standard service-level agreement between parties.

12.8 Samaritans will review this policy every two years unless requested sooner by Samaritans Research Team, Directorate and/or Board of Trustees.

RESEARCH ETHICS POLICY: GUIDELINES

1. Introduction

In 1996 the Board of Trustees approved a set of policy statements related to research activity within Samaritans. In 2009 the policy was revised and it was agreed that it would be updated every three years. Since then, the amount of research being carried out by Samaritans has increased, and it was considered essential that the previous policy be updated and amended to reflect this. The policy was updated to reflect current research practice within Samaritans and approved by the Board of Trustees in February 2013.

It is important to note that Samaritans research activity is separate from the provision of emotional support. It is thus governed by the Research Ethics Policy, to align with professional and ethical standards in research, and not by Samaritans' operational or service policies.

Samaritans is involved in a range of research activities, from surveys carried out by the internal research team with callers and volunteers, to collaborations with external researchers. Research enables the organisation to develop knowledge and learning about its activities, services, callers and volunteers. It enables the charity to contribute knowledge in the wider sector, especially in relation to suicide and emotional distress. It also enables the charity to provide evidence of the 'benefits' of Samaritans to callers and volunteers, and the impact of our support services on those who use them.

External researchers who collaborate with Samaritans or are commissioned and/or supported by Samaritans to carry out research will also have research ethics policies to which they are expected to adhere within their own organisations. Before commissioning or supporting research carried out by external researchers, it is essential that all parties review their research ethics polices and agree the ethical approach to the research.

This policy applies to all Samaritans staff, branches and volunteers who are involved in commissioning or conducting research projects on behalf of Samaritans. It also applies to external researchers who have been commissioned or supported to carry out research on behalf of Samaritans. Research projects must be developed within a set of criteria:

1. All research projects are communicated to and discussed with the Senior Research and Evaluation Manager at General Office before any agreement to undertake the research is made.

2. Anyone carrying out research on Samaritans' activities, services, callers and volunteers must be skilled and able to undertake research appropriately; research students may also undertake such research but must be under the supervision of experts at their academic institution. This also includes any Samaritans' volunteers that want to carry out research.

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3. All research projects must be presented as a research proposal, detailing the background, aims, objectives, research questions, methods, timescale, resource implications and dissemination activities and sent to the Senior Research and Evaluation Manager.

4. All research proposals will be evaluated on an individual basis, dependent on its aims, methodological approach and dissemination plans, alongside organisational research priorities.

5. All research projects must adhere to Samaritans' Research Ethics Policy and complete an Ethics Application. If projects are being carried out by external researchers, they must also provide evidence of ethical approval by the ethics committee of their hosting institution/organisation.

6. Each research project will be monitored by the Research Manager leading the project at General Office to ensure that its conduct is in line with the agreed protocol.

This policy will inform ethical judgements and decisions as to how research projects are structured and conducted, to maintain the privacy, rights and dignity of all involved.

2. Ensuring Well-being of Participants

A range of people is involved in Samaritan's research, including members of the public, volunteers, staff from a variety of organisations, and vulnerable groups, including past and present callers. Those responsible for research need to think through the ethical issues involved, to ensure that the physical, social and psychological well-being of participants is not adversely affected by participating in research.

All researchers should address a number of key questions when embarking on a new research project. These include:

1. What are the possible risks and costs to participants, in terms of time, inconvenience, distress, or intrusions on privacy?

2. How will participants be made to feel comfortable to share their experiences with the researcher? How will a relationship of trust be established?

3. How will the project deal with participants who become distressed, who wish to withdraw from the project, or who disclose risk of immediate serious harm to themselves or others?

4. What are the implications of paying or rewarding participants?

5. What issues are raised by informed consent? Is any additional information or advice needed?

6. Is the research sensitive to any current needs and issues relevant to the research population?

7. Are there any particular concerns arising from the nature of the research or subject matter? For example, research on suicide-related internet usage may need to consider what content or information on suicide is provided to participants; research related to suicide methods must consider what detail related to methods should be excluded from publications.

8. Have diversity and inclusion issues been considered and addressed?

9. Are the findings of the research to be published in formats that are accessible to research participants and, if necessary, wider social groups?

10. What consideration has been given to these key questions when making decisions about research questions, data collection, or the interpretation and dissemination of research findings?

3. Informed Consent

Informed consent is required for all activities that involve contact between researchers (whether Samaritans staff or from an external institution) and research participants. Participants must be able to decide whether or not to take part in the research, having been made aware of exactly what will be entailed by their participation. Participants need to be informed about the amount of time they will have to commit and any potential negative or distressing outcomes they might experience as a result of their participation.

Participants must be explicitly informed that it is their choice whether or not to participate in research, and researchers must ensure that individuals do not feel pressured to participate. Researchers need to recognise and uphold the rights of those who might not fully comprehend the aims or methods of a piece of research, and who might feel intimidated by the research process. Gaining informed consent must also include ensuring that participants realise that they can withdraw from the research at any stage, for any reason (see appendix 2 for an example of a consent form).

Where the participant is aged under 16 years, the parent/carer of the young person must be informed about the research, and asked to provide consent for the young person to participate. An exception is when the following situation pertains:

- When research is being carried out within a school, the school itself can make a decision about whether their pupils can participate in research, and can act in *loco parentis* in this respect. However, this should not prevent all parents/carers of the

young people being informed of the research, and for the school to provide 'opt-out' options enabling parents/carers to remove their child from participating in the research if they so wish. In addition, the school must secure the individual consent of each young person involved through age-appropriate means.

All research that involves children and young people must adhere to any legislative requirements regarding child protection in the country in which it is carried out. For cross-nation projects involving vulnerable populations and participants who may need on-going support, it may be necessary to gather independent and ethical advice if more than one legal framework surrounding data protection or child protection applies.

Informed consent is an on-going process. This is especially relevant when dealing with service users with mental health problems, memory problems, or a learning difficulty. Recalling information may be difficult for some service users and groups and therefore it is important to reaffirm key information relevant to the research in a clear and accessible way on regular occasions.

It is possible that these processes to gain informed consent might reduce the number of people willing to participate in a research project. However, it is necessary to ensure that participants are subjected to the minimum amount of distress and have clear expectations of what to expect, and that the charity is acting ethically.

4. Confidentiality and Anonymity

Those who agree to participate in research must be informed about the level of confidentiality and anonymity offered by the project. A full explanation of what this means in practice should be given. Confidential information can only be passed on to relevant parties if required or justified by law.

Participants must be informed of any limits to confidentiality. For example, for a participant involved in a case study, confidentiality and anonymity cannot be maintained if they agreed to be involved in a media event. The making of audio, video or photographic records of research participants can also remove confidentiality and anonymity, requiring these participants to provide informed consent in relation to the making of the material and how it will be accessed and used. It is also important to clarify within group work for data collection purposes (e.g. focus groups) that, when information is shared, it must remain confidential within that group and must not be passed on to any third party outside the group. It is essential to inform group participants about the identities of those who will be attending the group so they are aware who they will be discussing and sharing information with, e.g. staff and third parties.

During the process for gaining informed consent participants must be told that confidentiality may be reduced if they disclose that they or someone else is at risk of immediate serious harm. Where this happens the researcher has a duty to inform their manager to discuss the most appropriate approach to managing the disclosure (*see section*

7 Disclosure). Research is not a form of emotional support, and therefore does not have to be consistent with Samaritans Confidentiality Policy.

5. Use and Dissemination of Information

At the beginning of the research participants must be informed how the data will be used, for example, as statistical information, individual quotes, or case studies. They should also be told in what formats the information could be reported, for example, as books, journal articles, training materials and in conference presentations. Whatever the use of data or format in which it is reported, it is important to stress the level of confidentiality and anonymity provided by the project.

The researcher should:

- Only collect information that is relevant to the purposes of the research, or as is required by law.

- Report the research approach, methods, analytical tools and results in sufficient detail that they are understandable to any person who accesses the research, and allow other researchers to replicate their approach.

Research participants should, wherever possible, be given feedback about the results of the research. The participants should be told about the nature of the feedback they will receive at the beginning of the project. At times it may be more appropriate to feed back to organisations rather than individuals, but it is the researcher's responsibility to ensure that all those who participated receive feedback if requested.

The contribution of any persons to the research may be acknowledged, for example researcher and those involved in the generation of ideas, fieldwork, analysis of results, and report writing. Any academic research papers and publications that inform the project must also be suitably referenced. All named contributors must be fully informed of, and agree to, acknowledgements before publication.

Research which is not carried out to high standards and within strict ethical guidelines can cause serious problems for Samaritans. Misleading or incorrect information that is disseminated to external audiences may negatively affect the public image of the charity. It should also be noted that local research and dissemination activities may be picked up and reported nationally. In all instances where a research project is being designed or undertaken, dissemination of findings, the limitations of the research, how the research can be used, and any implications of the evidence for Samaritans must be considered.

6. Data protection

Participants should be informed that, in accordance with the Data Protection Act (1998), they have a right to see any information that Samaritans holds in relation to them. However,

participants must be made aware that Samaritans may hold data that is not identifiable and therefore may not be able to provide data, if requested.

Under the Data Protection Act (1998), any person or organisation processing personal information must comply with eight principles of good information handling. These state that the data must be:

1. Personal data shall be processed fairly and lawfully.

2. Personal data shall be obtained for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.

3. Personal data shall be adequate, relevant and not excessive.

4. Personal data processed shall be accurate, relevant and not excessive.

5. Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.

6. Personal data shall be processed in accordance with the rights of data subjects.

7. Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.

8. Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensure an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

In order to meet these data protection requirements, strict adherence to the ethical guidelines on informed consent and professional practice is required. In addition, all electronic information pertaining to research participants should be kept in password-protected files, and any hard copy materials containing personal or sensitive information must be secured in a locked cabinet. Access to electronic and hardcopy materials should only be given to designated researchers and those identified as requiring essential access to the information.

1. Disclosure of Risk of 'Immediate 'immediate serious Harm' All Samaritans' research applications and projects are considered by the Research Team at Samaritans General Office to ensure they adhere to the Research Ethics Policy and will not put the organisation at any risk.

2. Where a project is designed internally by the Samaritans Research Team in General Office, the research proposal and plan must contain a section on ethics. This must clearly set out all ethical considerations for the particular project, how the project meets the requirements of Samaritans Research Ethics Policy, include a copy of the information and consent forms for participants and specify the definition and process for managing disclosures of immediate serious risk of harm for that particular project. This must be approved by the Policy and Research Steering Group, which is chaired by the Executive Director for Policy, Research and Development and includes (at least) one member of Samaritans Board of Trustees, with sufficient standing and research expertise to provide guidance and oversight of research activity and ethics.

3. Samaritans branches must ensure that any external research projects which they commission, support or undertake are carried out ethically and adhere to this policy. They must obtain written confirmation from the Senior Research and Evaluation Manager at General Office that the research does adhere to this policy. The Research Team at General Office must be informed about any research in which a branch is involved. It is also important to ensure coordination and sharing of findings across Samaritans. The Research Team is able to provide support and expertise to branches in conducting research.

4. Samaritans is committed to employing qualified and competent researchers. All its researchers must receive regular line management to ensure that ethical issues are discussed and addressed.

5. All Samaritans' researchers are subject to checks by the Criminal Records Bureau.

6. Samaritans is committed to ensuring the personal safety of researchers. It will encourage the use of mobile phones and identity cards, and the use of a monitoring system for checking researcher whereabouts and activities.

7. In the case of research undertaken (under commission) by external agencies (including research institutions, universities, market research companies), a full copy of the ethics policy must be issued to the organisation acting on behalf of Samaritans, prior to the commencement of work, to promote adherence to policy and guidelines. External agencies must also have their own ethics policy which should be reviewed by Samaritans prior to contract. In addition, researchers based in external institutions or organisations with an Ethics Committee must produce evidence of ethical approval for the research and evidence of data protection policies.

8. Standard service-level agreements covering ownership of information, copyright and citation privileges, access to data, data protection, and publication needs are required prior to the commencement of work conducted by any external agency.

Adherence to Samaritans' ethics policy will be required as a key component of the standard service-level agreement between parties.

9. Samaritans is committed to following the ethical procedures and requirements of other bodies with which they collaborate or which are involved in research with the charity.

10. Samaritans will review this policy every two years unless requested sooner by the Research Team, Directorate, and/or Board of Trustees at Samaritans General Office.

Research activity does not aim to provide emotional support and is distinct from Samaritans support services. Research activity is governed by the Research Ethics Policy, which seeks to ensure adherence to the professional and ethical standards of research, rather than Samaritans' service or operational policy. This means that Samaritans' service policy on confidentiality and disclosure of risk does not apply. When someone uses Samaritans services they do so based on Samaritans' service policy. When someone takes part in research for, by or related to Samaritans, they agree to take part based on the terms of the research project, which are made clear through the process of informed consent. The consequences of disclosure in the research project, and how these differ from disclosure in the course of using a Samaritans' service, should be clear to service users and research participants.

Immediate serious harm can refer to situations such as being at risk of, or experiencing, physical, sexual, mental or emotional abuse, or poor emotional and mental well-being. However, in research projects that are exploring the experiences of vulnerable groups, 'immediate serious harm' can be hard to define and apply in practice. 'Immediate serious harm' needs to be defined by the researcher for each specific research project. A clearly defined approach for researchers to respond to such disclosures must also be agreed (see appendix 3). This needs to be made explicitly clear to participants so that they are aware of the possible consequences of any disclosures they make.

If a research participant discloses that they or someone else is at risk of 'immediate serious harm', the researcher has an obligation to refer the participant for support and possibly refer the risk to a third party. In such cases, the researcher must inform the participant about the next steps and if the disclosure will be referred to a third party. Ideally, consent should be sought from the participant before a disclosure is referred to a third party. However, it should be noted that some research projects may require the passing on of research participants' details and disclosed information to a third party without consent – although this would always be the last resort, as the participants' permission would be sought first. Essentially, this adheres to informed consent which is the cornerstone of research ethics. Throughout this process, the researcher must gain support from their manager in order to agree the most appropriate actions to take.

Therefore, although there are no firm guidelines concerning responses to a disclosure of risk of immediate serious harm, there is a process to which researchers must adhere. The aim is

to ensure that the appropriate information and considerations are in place so that any disclosures are managed ethically. Researchers are responsible for defining the boundaries of the research so that disclosures of immediate serious harm can be recognised and addressed. For example, in a research project exploring the experiences of those who self-harm, it would not affect confidentiality if a participant disclosed that they self-harmed. However, if the same participant disclosed they harm others in their care, this information would have to be managed as a disclosure.

There may be times when a research participant is not considered at risk of immediate serious harm, but the researcher is concerned about their well-being. In such circumstances, the researcher should ensure that the participant receives information about organisations that can provide appropriate support.

8. Expenses and Payments

All participants should receive reimbursement for reasonable expenses incurred, such as travel expenses. Samaritans has no policy about payment for participating in research. However, any decision about payment for participation must be made on a project by project basis, based on considerations of the effect of payment or non-payment on participation and the availability of funds.

It is acceptable to provide participants with an incentive to take part in the research, such as a prize draw. Also, where particular organisations or institutions have supported the research it is acceptable to provide a thank you, such as providing resources for an organisation's library. Researchers must not accept gifts as this can undermine impartiality.

9. Researcher Conduct

Researchers employed by Samaritans or based at an external institution or organisation must ensure high levels of professional conduct. This refers to how researchers manage their own behaviour, and how they manage and present research data.

Researchers must ensure that they are presenting research evidence, data, findings or conclusions from the project accurately, and must never purposefully fabricate, falsify or misrepresent research findings. Researchers should also act in such a way that they do not jeopardise future research, the public standing of the field or Samaritans, or the publication of results.

10. Complaints

Complaints arising from, or related to, research should be referred to the appropriate member of staff at Samaritans General Office.

Complaints from research participants should be referred to the Research Manager/Lead responsible for the project. However, when the Research Manager/Lead is involved in the

complaint, it should be referred to their line manager. Details of the complainant and the complaint will be recorded at this point and a case-by-case response made. Additional information may be sought from General Office staff involved in the research process to clarify the most appropriate response to any complaints of this nature.

Complaints from the general public about the nature of research and research inclusion should be referred to Head of Policy & Research for initial processing and follow-up. Additional information may be sought from General Office staff to clarify the most appropriate response to any complaints of this nature.

Complaints by funders or research partners should be directed in the first instance to Head of Policy and Research, and if additional support or advice is needed it must be escalated to the Executive Director of Policy, Research and Development. It is important to note that a clear and agreed Service Level Agreement at the commencement of the research process will usually prevent such situations arising.

11. Internet Mediated Research

Internet Mediated Research (IMR) applies to a range of research activities including observational studies, surveys, and controlled experiments. IMR requires the same ethical considerations and practices as research carried out in more traditional settings; however, there are additional ethical issues that need to be considered and applied.

Research projects that adopt IMR must consider whether it is the most appropriate approach for the research and for the sample population. If it is essential to identify participants or be able to restrict who can and cannot participate, IMR is unlikely to be suitable. Additionally, as the researcher has little control over who takes part and in what kind of environment, the impact on the composition of the sample and the quality of data collected needs to be fully considered.

Research conducted online results in a permanent record unlike research in more traditional face-to-face settings. Participants may consider online participation to be 'private' even though in some instances it can be traceable and become public. Therefore, issues around privacy need to be explored for each project adopting IMR, and any risks to privacy need to be made clear to participants. When recruiting participants for IMR through email, researchers need to consider any risk due to the use of non-secure emails and legislation regarding unsolicited 'spam' emails. When observing discussion forums, researchers must consider the legitimacy of using deception and whether this poses an ethical risk to the research. For researchers carrying out IMR, it is important not to blur the boundaries between personal and professional, and only use professional contact details for the purposes of the research.

In the case of IMR projects that use observation (e.g. observing behaviour and use of chat rooms), ethical guidelines suggest that, where consent has not been gained, observations should only be made in environments where people would 'reasonably expect' to be

observed by strangers. Therefore, when researching environments or online forums that are considered to be private, using observational methods needs to be considered carefully, taking into account invasions of privacy, levels of intrusiveness, and any risks to participants.

The level of confidentiality available to research participants needs to be made clear. Full confidentiality cannot be guaranteed since the researcher cannot control the networks. For example, email content may be stored by web hosting companies. Therefore, researchers need to inform IMR participants how the data they provide are to be electronically stored and transported. If participants post any information online for the purposes of the research, they must be informed that this could be seen by the public via search engines. Unless a participant has provided consent, researchers need to consider how reports of any data obtained from the internet could pose a threat to a participant's privacy, e.g. using a participant quote that could be traced through a search engine.

In common with research carried out in more traditional settings, anonymity must be guaranteed for IMR participants. However, for IMR this also applies to website addresses, discussion forums, and pseudonyms used by participants. This is to minimise the risk that any participant becomes identifiable.

Researchers need to consider whether IMR is suitable for participants who require permission to participate from a parent/carer, e.g. those aged under 16 years. This will depend on the nature of the research and the complexity of gaining consent from both the participant and the parent/carer. However, while this may be complex, IMR can still be considered for these groups, especially when young people use the internet daily. It is important to consider the research project, and whether IMR would enable the research aims to be met with groups where dual consent is required.

It is possible that participants involved in IMR do not fully read information sheets or instructions before participation. Therefore, to encourage participants to read information and thus be fully informed before consenting to take part, information such as the information sheet and consent form should be provided in a simple and accessible format. Participants must also be aware that they could incur costs if using a 'dial up' internet access, and how long their participation will take.

In order to ensure that IMR participants feel able to withdraw from the research without any consequence and do not need to give a reason, researchers must make it a clearly defined option. For example, researchers could provide 'opt-out' options throughout the research instrument, and provide the researchers' contact details to enable the participant to ask questions or raise concerns. Where possible, researchers could also ask participants to allocate an ID code to their data to enable it to be identifiable if they wish to withdraw it from the dataset. However, participants must be made aware of the cut-off date where the data will be analysed for the purposes of the research and their data will therefore become anonymised and untraceable. If ID codes remain in the database, these must not be used as part of the analysis or presentation of data.

A debrief page should be provided to ensure (as far as possible) that IMR participants are clear about what will happen after they have participated in the research. Researchers can also consider providing a debrief page for those who opt-out of the research, to ensure that all participants are aware of how their data will be used. Researchers also need to determine whether they will use partly submitted data by participants who opt out before full participation in the research. This could be done by providing an opt-out option at all stages of the research – once a participant chooses this option they receive the debrief page. This is also recommended to ensure that all participants receive advice on support organisations they can access if required after participating in the research, especially if sensitive materials that may have an impact on a participant's well-being have been used. In the case of IMR this is even more important, since the researcher does not have physical contact with the participant and cannot therefore determine if support is needed.

All research participants are entitled to receive feedback on the research findings. This can sometimes be difficult for IMR participants who are not in physical contact with the researcher and very likely to be anonymous. Researchers therefore have to consider how they will provide participants with feedback and how they will disseminate the research findings. One possibility would be to provide a link to the location where feedback on the research will be placed.

12. Process and Organisational Matters

Samaritans is committed to maintaining the highest ethical standards and achieving best practice. The following processes are essential to the achievement of these objectives:

1. All Samaritans' research applications and projects are considered by the Research Team at Samaritans General Office to ensure they adhere to the Research Ethics Policy and will not put the organisation at any risk.

2. Where a project is designed internally by the Samaritans Research Team in General Office, the research proposal and plan must contain a section on ethics. This must clearly set out all ethical considerations for the particular project, how the project meets the requirements of Samaritans Research Ethics Policy, include a copy of the information and consent forms for participants and specify the definition and process for managing disclosures of immediate serious risk of harm for that particular project. This must be approved by the Policy and Research Steering Group, which is chaired by the Executive Director for Policy, Research and Development and includes (at least) one member of Samaritans Board of Trustees, with sufficient standing and research expertise to provide guidance and oversight of research activity and ethics.

3. Samaritans branches must ensure that any external research projects which they commission, support or undertake are carried out ethically and adhere to this policy. They must obtain written confirmation from the Senior Research and Evaluation Manager at General Office that the research does adhere to this policy. The Research

Team at General Office must be informed about any research in which a branch is involved. It is also important to ensure coordination and sharing of findings across Samaritans. The Research Team is able to provide support and expertise to branches in conducting research.

4. Samaritans is committed to employing qualified and competent researchers. All its researchers must receive regular line management to ensure that ethical issues are discussed and addressed.

5. All Samaritans' researchers are subject to checks by the Criminal Records Bureau.

6. Samaritans is committed to ensuring the personal safety of researchers. It will encourage the use of mobile phones and identity cards, and the use of a monitoring system for checking researcher whereabouts and activities.

7. In the case of research undertaken (under commission) by external agencies (including research institutions, universities, market research companies), a full copy of the ethics policy must be issued to the organisation acting on behalf of Samaritans, prior to the commencement of work, to promote adherence to policy and guidelines. External agencies must also have their own ethics policy which should be reviewed by Samaritans prior to contract. In addition, researchers based in external institutions or organisations with an Ethics Committee must produce evidence of ethical approval for the research and evidence of data protection policies.

8. Standard service-level agreements covering ownership of information, copyright and citation privileges, access to data, data protection, and publication needs are required prior to the commencement of work conducted by any external agency. Adherence to Samaritans' ethics policy will be required as a key component of the standard service-level agreement between parties.

9. Samaritans is committed to following the ethical procedures and requirements of other bodies with which they collaborate or which are involved in research with the charity.

10. Samaritans will review this policy every two years unless requested sooner by the Research Team, Directorate, and/or Board of Trustees at Samaritans General Office.

Definitions used in this Policy

Research: External research is conducted within research agencies such as universities by academics/researchers in order to describe, explore and understand social life of groups and individuals. Broadly, research can be carried out using a quantitative or qualitative approach, or a combination of both. Quantitative methods aim to quantify information and collect data, using methods such as questionnaires, surveys, and secondary analysis of data. In comparison, qualitative methods explore personal experience and aim to understand the meaning behind experience, and use methods such as focus groups, individual interviews, participant observation, and case studies.

Evaluation: Evaluation refers to the gathering of information to make judgments about a particular project or service, and using that information to inform development and enable change. In common with research, data can be collected through quantitative, qualitative or mixed methods. However, unlike research, the aim of an evaluation is to determine the value and impact of a service or project and use its findings primarily for service and/or project development.

Researcher: Any person carrying out research or evaluation with or on behalf of Samaritans. This could mean external researchers commissioned by the Central Charity or volunteers in Samaritans branches. However, in most instances, the term researcher will apply to the Research Team at Samaritans General Office, and researchers or research students based at external research institutions who are conducting research or evaluation projects with or on behalf of the charity.

Research Skills: In order to carry out quality research within a strict ethical framework, several skills are needed. These include project design, planning and monitoring, designing and using qualitative and quantitative methods, data analysis, writing reports and publications, and designing and carrying out a dissemination plan. It is vital that anyone who wants to undertake research with or on behalf of Samaritans has these skills and seeks advice and support from the Senior Research and Evaluation Manager at General Office for the following reasons: There are important reasons as to why advice should be sought from the Senior Research and Evaluation Manager before beginning a research project:

1. To ensure that the project is designed and carried out appropriately.
2. To ensure that the project is carried out ethically to protect participants, researchers, and the reputation of the organisation.
3. To ensure that the research project has been discussed and agreed with relevant persons.
4. To ensure that the research is needed and not an unnecessary duplication of current evidence.
5. To ensure that the project findings are used appropriately and not manipulated or used to make false claims.
6. To ensure that publications and dissemination of the research findings are appropriate and do not result in any risk for the organisation.

APPENDIX 1

SAMARITANS CONFIDENTIALITY POLICY (FOR INFORMATION PURPOSES ONLY)

Samaritans has a policy of caller confidentiality, which is fundamental to our service. In circumstances where a person contacts Samaritans services by phone, email, letter, minicom or face-to-face, the following policies and procedures apply:

All information relating to a caller is confidential to Samaritans unless:

- We have informed consent from a caller to pass on information
- We call an ambulance because a caller, on branch premises, appears to be incapable of making rational decisions for him or herself, e.g. as a direct result of self-harm
- We receive a court order requiring us to divulge information
- We are passed information about acts of terrorism or bomb warnings
- A caller attacks or threatens volunteers
- A caller deliberately prevents the service from being delivered to other callers.

Samaritans maintains confidentiality even after the death of a caller.

Note: Samaritans Confidentiality Policy does not apply within the context of research. See section 1: Application of the Policy.

APPENDIX 2

RESEARCH PARTICIPANT CONSENT FORM (EXAMPLE)

By signing this form you are giving your consent to taking part in a Samaritans research project titled [project title here].

1. I confirm that I understand the purpose of the research and what participation will involve. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. ☐
3. I understand how the information I provide will be recorded and stored. I can request a copy of my data (unless unidentifiable) at any time. ☐
4. I am aware that the information I provide will be used for the purposes of the research unless I decide to withdraw the information (which I can do at any time). ☐
5. I understand that all data collected will be anonymised before it is published or presented and that all the information I have given is confidential unless I agree otherwise. ☐
6. I am fully aware of how the information I provide may be used and presented in publications, e.g. quotes. ☐
7. I am aware how the information I provide will be managed and used by Samaritans in their internal and external work and publications indefinitely. ☐
8. Any expenses I incur will be reimbursed where it is deemed as reasonable. ☐
9. I have been provided with the contact details of the researcher so that I can raise any questions in relation to the research and my participation. ☐

If there are any issues above you do not understand, please ask for clarification before signing this consent form.

Signature of research participant

I have read and fully understand the consent form. I provide my signature as consent.

Name (in full): _____

Signature: _____ **Date:** _____

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APPENDIX 3

Samaritans Procedure for Managing Disclosures of Risk of 'Immediate Serious Harm'

There is no consensus as to what constitutes 'immediate serious harm' which, if disclosed to a researcher during the research process, should result in the researcher providing information to a third party. How risk of immediate serious harm should and can be assessed and responded to will differ depending on the sample population participating in the research and the research topic area. The aim is therefore to ensure that for every research project a sufficient process is put in place as part of the research plan to ensure that any disclosures are managed appropriately.

Below are a series of questions to consider when planning and conducting research, and when managing a disclosure of risk of immediate serious harm. These questions need to be addressed and discussed between the researcher and their manager or other relevant parties.

1. Have you clearly defined what would constitute a disclosure of 'immediate serious harm' for your research project?
2. Is the disclosure of risk of immediate serious harm to the participant, to another person (adult or child), or to society, i.e. bomb threat?
3. What is the risk of immediate serious harm that has been disclosed?
4. Are there any issues relating to the disclosure that are not clearly understood by the researcher? Is more information needed and is this possible?
5. If action is not taken with regard to the disclosure of risk of immediate serious harm, will the risk continue? Is this acceptable?
6. What are your reasons and justifications for contacting a third party?
7. Does the disclosure of immediate serious harm need to be managed quickly due to the nature of the risk? If it isn't managed quickly, will there be any possible implications to those at risk or to others?
8. How will you inform the participant who disclosed the risk of immediate serious harm that you will be referring the information to a third party? Have you been able to gain their consent before information is referred?
9. What implications will informing the participant and/or gaining their consent that their disclosure will be referred to a third party have on the risk of immediate serious harm? Will the research participant change their behaviour to minimise or hide the risk that was disclosed?
10. Do you need further advice from a relevant expert before passing information to a third party due to a disclosure of risk of immediate serious harm?

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