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# **PRO**moting integrity in the use of **RES**earch results in evidence based policy: a focus on non-medical research

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0.3

# EXECUTIVE SUMMARY

This Report focuses on the work done specifically to further the construction of the PRO-RES Framework. Links to the original proposal have been maintained after the initial consultations that have taken place. The proposed Framework design continues to seek a sequential, query-responsive access to a repository of advice, guidance, good practice templates and recommended links seen as useful to the full range of stakeholders. We are focusing on the concept of 'ethical advise' to policy makers.

- We will write a code for seeking/using ethical evidence from non-medical research to inform policy. It needs to be short, clear, succinct and actionable. We call this 'The Accord'<sup>1</sup>.
- 2. **A toolbox**, which is a demonstration of the Accord in action and that can be used by policy makers and their scientific advisors during the policy making process, to help them understand the ethical issues arising from the advice process (more details bellow).
- 3. We will also provide additional resources, to visitors/readers, in order to be able to provide them with support when exploring the Accord and toolbox. There resources will be varied and will include in-depth publications on the principles and ethical issues that the Accord explores, links to other similar projects, links to case studies etc. The summary of all items in the website, including the Accord, the Toolbox and the other resource will the **PRO-RES Framework.**

The actions taken so far include several live, and many more virtual, meetings between the Partners to plan the overall style of the Framework and its substantive content. Effective workshops were seen as a key constituent and effort was put into ensuring they deliver the necessary outcomes. Content planning, shared templates to target attendees, and key 'lessons learned' will enable planning for the next round of workshops. Omissions of adequate ethics codes/guidelines at the national level will have to be identified. This, together with active contributions to the mapping of codes and guidelines and building the stakeholder list, help maintain the focus of the planned Framework.

A pilot, provisional draft version of what some items/resources of the Framework might look like and what it might include is supplied. Key elements include a glossary of terms and concept definitions, suggestions for access to advice on research ethics and scientific integrity, some sample illustrative case studies raising concerns for ethics and integrity, links to key codes/guidelines, the 'in-house' mapping of such.

Subsequent actions to be implemented involve the actual design of the interactive platform, continued seeking of suggestions for substantive content for the resources, and a plan for content management and sustainable platform evaluation and management.

<sup>&</sup>lt;sup>1</sup> The name is not finalised.

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# RATIONALE: ORIGINAL PROPOSAL

### Preamble:

### This report focuses on the work done specifically to further the construction of the PRO-RES Guidance Framework together with offering a preliminary Draft version of the proposed Framework itself.

The key elements of a provisional framework have been set up and are next to be tested first with consortium partners and then with a broader range of stakeholders (Task 1.3). The provisional framework was based on information gathered in Tasks 1.1. and 1.2, (drawing on and in response to previous such work) and is targeted at a range of 'levels' which will be practically applicable to non-medical research from undergraduate to funded professional research agencies. (Research on animals has a separate ethical and regulatory regime. Research 'with' animals may not be equally well covered. Hence PRO-RES has yet to decide whether or not it can/or wishes to cover research on or with animals.) This first draft of a provisional framework has been created by AcSS based on their experience and initial meetings, enquiries with stakeholders and the first 'High-Level Discussion' (WS1). It will next be tested with the consortium partners, then fed in to WP3 and as part of the dialogue input for the WP2, the consultation process.

As planned, the provisional Framework includes a range of 'levels', applicable to non-medical research. The first stage outlines underlying values such as beliefs in democratic practice, inclusivity, respect for diversity, freedom of action, a right to privacy, shared benefits from research and harm minimised and how such values can be expressed in the form of principles and standards. All are to be explicated in the selected resources that the Framework will suggest access to. The 'routes' into the Framework are via 'stakeholder roles' so that the stakeholder interests can be met directly with resources relevant to their needs. Account has been and will continue to be taken of previous foundational work, examples of good practice and the available range of resources, templates, SOPs and so on. Links to recent and concurrent related projects on research ethics and scientific integrity are being maintained to ensure no excessive duplication of effort occurs and that due acknowledgement is made of sound, valid and relevant ongoing work.

# **ACTIONS TAKEN**

2.1 *Cluster projects meeting* (1<sup>st</sup> June 2018): Note was taken of the range and detail of existing – concurrent and previous – projects related to research ethics and research integrity projects funded under SWAFS 2014-15and SWAFS 2016-17. Ongoing networking with such projects and links to their activities via PRO-RES was to be conducted, and, reciprocally, it was requested that such projects maintain links to PRO-RES.

2.2 KickOff Meeting: Discussion guided the mapping of existing research ethics/integrity codes/guidelines/'frameworks' (based on the UT template developed for PRINTEGER), modified for PRO-RES purpose by adding categories/criteria if necessary and expanded to include 'research ethics' codes etc. Similarly, the mapping of stakeholders needed to be broad initially and refined later as necessary. All categories of stakeholders for non-medical sciences were to be included: such as ethics reviewers, research managers, researchers, regulators, policymakers in the fields of research and any who might be interested in research ethics and integrity. This was to be at institution level or large group level/network level with a target of influential individuals if they are known. It became increasingly clear that a 'Guidance Framework' is what we aim at – not repeating another set of codes etc. The Framework will act as a resource where people can find the best material for their needs, including, for example, ethics advisors per subject area/topic, or SOPs for research ethics review committees and so on. It was agreed not to advise any formal regulation. This should be left to the community/regulators themselves to select the most appropriate elements from the Framework if they wish to move to regulation. This is part of the separation of research governance from ethics review. We need to show how to do it and that there are good examples. Part of our job is to convince the policy makers that this is the way forward. Ultimately, the EC must endorse it and advocate its use in FP9 (Horizon Europe).

2.3 *PRO-RES consortium meetings*: Continued to endorse the approach established at KickOff. That was to include: a 'Guidance Framework' not another code; a mapping of existing codes and guidelines with a matrix that could be interrogated and incorporated into the Framework; an effective stakeholder list of individuals and organisations that could be selectively invited to planned workshops and invited to comment on the developing Framework.

2.4 *AcSS Team meetings*: Tasks were allocated to team members and roles for the production of contributions to actions assigned. Internal guidance and advice was incorporated into the initial Draft Framework and will guide its future development. AcSS team thus contributed to deliverables and planning across the Work Packages.

2.5 *WS Planning meetings*: Several meetings outlined the necessary style of the planned workshops (designed as 'high level discussions') and what was to be sought from them. Specific questions were set for participants to aid in the Framework

construction. A short PRO-RES outline presentation was supplied that can be used in each of the subsequent workshops.

2.6 *WS lessons learned*: While there was endorsement of the stated PRO-RES approach (construction of a 'Guidance Framework' which could be commented on by the full range of stakeholders), the more active participants remained either proud of or protectionist of their own domains of interest. The subsequent challenge to further workshops would be how to ensure they remain effective in helping to develop a Framework that will be seen as relevant to the full range of stakeholder needs without impinging on or 'challenging' existing good works.

2.7 Contributions made by AcSS to:

*Codes, guidelines mapping:* Suggestions were inserted into the codes/guidelines spreadsheet and supplementary suggestions sent. Comments then made on D 1.1 together with decision on where to place the final matrix within the Framework. (Opportunities to continue to update the matrix must be provided as new entries are suggested by site visitors and/or stakeholders.)

*Stakeholders database:* Suggestions were made both in terms of relevant organisations and effective named individuals (permissions sought).

*WorkShop 'concept' plans*: Following the KickOff and Cluster meetings the concern was to ensure effective workshops – hence small size, key people invited, cast as 'High Level Discussion'.

*Chair's welcome to WorkShops:* A standardised welcome message was drafted to be used as a welcome message for all workshop attendees, including the specific questions we need attendees to focus on. This was seen as part of a series of strategies to ensure the WorkShops produce effective outcomes.

*Mission Statement:* This was drafted as a succinct means to ensure all Consortium Partners were agreed on how to promote, advertise and explain the goals and aims of PRO-RES generally (publicly) and more specifically for stakeholders and attendees.

# FRAMEWORK 'STYLE'

To be effective the PRO-RES Framework must act as a model for good practice: a basic, punchy, ethical practice 'culture', that is also 'discipline-neutral'. While being self-evidently user-friendly it must be of practical use and relevance to all stakeholders accessing it.

*Interactive platform structure*: This style is seen as being best achieved by ensuring some degree of interactivity – that users can source relevant material, contribute relevant material and engage in dialogue with experts via the platform.

### THE IDEA BEHIND THE FRAMEWORK

Our approach is predicated upon the fact that Oviedo and Helsinki are not codes. Helsinki is a 'declaration' promoted by the WMA based on a series of principles – no foundational values are discussed. It took 8 successive iterations between 1964 and 2008 to achieve its current status. Modifications and clarification became necessary as the detail for implementation was

tested and challenged. Their target audience is focused and 'narrow': physicians and medical researchers and it can be promoted at a 'global' level due to the WMA hosting and developing it. Oviedo is called a framework 'convention' formulated by the Council of Europe established in 1997 but supported since then by additional protocols. So it is European in coverage and established by treaty. But as a convention, it requires individual States to establish their own legislation. Germany for example has never ratified it and there is little evidence for the impact or effectiveness of Oviedo and Helsinki.

We are not opposed to taking a 'normative' position. Rather we thought it inadvisable for many reasons to attempt to make whatever we produced too 'prescriptive'. We recognized this in the proposal (and in the DoA) and so we made a case for a user-friendly 'Framework'.

Another issue to note is that it is impossible to draw up a code that can be comprehensively followed by all RPOs. At least, not *all elements* of such a code can be followed by all RPOs – we make this point in referring to the emergence of a problem during the first phase of workshops that think tanks and advocacy agencies, for example, cannot agree with all the principles. We are planning to further explore this issue in our consultation process.

Taking to heart the lessons learned from the first phase of the project and the advise given to us by various stakeholders, we decided to refocus the project in a two-part final outcome:

- We will write a code for seeking/using ethical evidence from non-medical research to inform policy. It needs to be short, clear, succinct and actionable. We call this 'The Accord'<sup>2</sup>.
- 5. **A toolbox**, which is a demonstration of the Accord in action and that can be used by policy makers and their scientific advisors during the policy making process, to help them understand the ethical issues arising from the advice process (more details bellow).
- 6. We will also provide additional resources, to visitors/readers, in order to be able to provide them with support when exploring the Accord and toolbox. There resources will be varied and will include in-depth publications on the principles and ethical issues that the Accord explores, links to other similar projects, links to case studies etc. The summary of all items in the website, including the Accord, the Toolbox and will the **PRO-RES Framework**

Thus, we believe that from now on, the Accord/Code of PRO-RES will be evident to all and open to comment and amendment at least for the life of the project. Considerations for its sustainability will of course be needed at a later stage.

The Accord will be constructed initially by the project and will become the first draft. This will be the initial base of discussions for the consultation actions of WP2 and we will aim to build up from that base.

The toolbox will be constructed, as a generic demonstrative flow chart, that can potentially be used by policy makers and/or policy advisors. The toolbox will accompany the Accord.

<sup>&</sup>lt;sup>2</sup> The name is not finalised.

# Thus the Accord statement is only a part of the Framework which we conceive as a holistic, 'systemic' approach to supporting ethical evidence-based policymaking.

To more closely **resemble** Oviedo/Helsinki, the Accord statement will appear upfront as the first page of the website and the Framework. Users can then step though each of the subsequent supportive materials and resources. The current sequence envisages the next level to offer more detail and a rationale for each of the succinct elements of the Accord statement, this will be followed by a toolbox designed to support implementation of the Accord in assessing the integrity and ethical status of any research evidence. This latter step resembles Oviedo more than Helsinki. Further steps offer a range of resources that help guide research to be funded, managed, assessed, conducted and disseminated ethically and with integrity.

While emulating Oviedo/Helsinki we recognize the potential for tokenism. To be effective, have impact and be seen as of practical value to all stakeholders we need '*continuous discursive engagement*' as suggested by an eminent attendee at our mid-term conference.

### Relation to Oviedo/Helsinki summary

To clarify and summarise our position on the relationship to Oviedo/Helsinki see the list below. Though neither claim to be prescriptive codes, they are often seen as such.

Helsinki is...

- a 'declaration' promoted by the World Medical Association (WMA)
- based on a series of generic principles
- without foundational values discussed or aired publicly on the website
- developmental taking 8 successive iterations (from 1964 2008).
- modified throughout as the detail for implementation was challenged
- targeted 'narrowly' at physicians and medical researchers
- promoted globally due to the WMA hosting it,

and was...

- beset by conflict, leading to resignations from the WMA
- contested as an authoritative source
- not legally binding
- valued in its potential to influence national legislation,

but...

- lacking evidence for its impact/effectiveness
- legislative impact dependent upon local variations.

(see Carlson, Boyd and Webb 2004)

Oviedo is...

- a framework 'convention'
- formulated by the Council of Europe

- established in 1997 but modified by additional protocols
- European in coverage and established by treaty

But...

- it requires individual States incorporate it in their own legislation
- not all have done so

While...

- only 35 countries have signed the Convention
- only 29 of these countries have ratified the convention
- significant non-ratifiers include: Belgium, Germany, Ireland, the Russian Federation and the UK.

We envisage that

PRO-RES...

- will not deliver a prescriptive code
- instead will develop an overarching normative Framework which will...
- offer succinct statements of values, principles, virtues and standards with a...
- background explanatory rationale and...
- supported by resources to aid assessment of ethically based evidence
- help researchers and RPOs produce evidence that is ethically sound
- support professional work practices conducted with integrity
- ensure that research practices are conducted with high levels of transparency
- offer advice and guidance to policy advisors and policymakers and include a toolbox that can be utilised as a list of *does and don'ts* that will guide the scientists when they are involved in science advice processes
- will offer recommendations about how best to create a culture of ethics and integrity in research practice.
- seek endorsement and support from key agencies with interests in ensuring best research practice
- be open to ongoing development, responsive to constructive modification.

Thus while Oviedo/Helsinki offer some 'standards' for PRO-RES to emulate, they also offer useful illustrations of the limits to what can possibly be achieved. In our view this powerfully endorses our approach to construct a Framework that advises, guides and supports while containing clear statements which resemble those found in Oviedo/Helsinki. If it also offers suggestions for regulatory mechanisms that could be a bonus. At this stage it is difficult to

advise on which regulatory mechanisms might work best. For example, the Accord, the Toolbox and the supportive resources in the Framework will attempt to specify the need to declare vested interests and possible conflicts of interest and how to actively manage those interests and any conflicts that are in many cases inevitable. For example if there are diverging schools of thought there will need to be way of disclosing such divergences and how they can best be addressed. Evidently the 'balancing' is often left to the policymaker (and their advisors) to gather all pieces of evidence and advice and weight them against each other in order to conduct an option appraisal. In essence that might be considered the very definition of policymaking, i.e. balancing the needs of groups and then deciding what is 'best'. Ultimately the Framework can only assist in such decision making, not conduct it for the policymaker. The signing up to the Accord statement is a way of suggesting making policy the 'best' interests of all - not just the narrow vest interests of any one group. Institutions can be offered advice and guidance on how that might best be achieved. Members of the consortium have already conducted an analysis and consideration with recommendations about how that might be accomplished in one complex area alone - that of 'dual use' (see Kavouras and Charitidis 2020). Endorsement by the European Commission would endow it with further authoritative force.

### The vision for the framework

The final form of the website can be summarised in the following diagram:



Figure 1: PRO-RES website/framework vision

The main idea is to include several 'levels' on the website that will enable visitors to extract as much information as they need/want:

**Level 1** – the root level of the website will immediately link to the succinct summary/code, the <u>'Accord'</u> (here named as Brussels accord. The name is still TBD....). The text would be visible in this case, with the blue boxes, denoting either links to information or a text box that can be expanded (in this case, the foundational statement.

**Level 1 is intended for everyone that visits**. A button to download the text in PDF form would also be available.

Scrolling down, you proceed to.....

**Level 2** contains more information on the theoretical work behind the Accord statements, including the **toolbox**, which would be a practical demonstration of the Accord in actions, a help for anyone that might want to use the accord in an ethics review.

Level 2 is indented for parties that have an interest of using the accord and get a better understanding of how it came about.

Further scrolling reaches:

Level 3 is a link to the <u>open access Publications</u> of the consortium . This should the material that is interested to academics that deal with ethics and integrity issues and will expand in depth on Level 2 issues, the consortium thematic investigations and other issues. See section 2 of this document for a proposed list of publications.

Level 4 will include direct output from the PRO-RES events and can be considered as input data that the project has received during its life time, from external stakeholders.

Other tabs on the website:

The '**PRO-RES Project**' box to the left, is a separate website tab that deals with project communication and contains the standard information regarding the identify of the partners, brief history of the project etc.

The **additional resources tab (to the right)** contain material that are useful to people dealing with ethical codes, either for learning, training or further exploration. Such material can be other relevant project, trainers, initiatives, list of relevant codes etc.

This can also be viewed as of interest to all stakeholders, as it has different use for different profiles.

Finally, **Search Function**, to allow navigation with keywords. This is implemented now although the keyword search can be improved to restrict results for certain keyworks (as of now, it returns all documents with the keywork, which can be overwhelming).

Evidently **printouts** of the Accord, the toolbox and the other available resources are possible (and some are already present in word documents or pdfs), however to enable responsiveness to recommendations, updates criticisms and edits, the virtual interactive platform is the most enabling method.

Some of the elements of the framework are explained in the next sections.

# BACKGROUND TO THE PRO-RES PROJECT

**MAIN GOAL:** PRO-RES aimed to use the full range of stakeholders, to devise and build a supported *guidance framework* for all non-medical sciences and humanities disciplines adopting social science methodologies. The framework is intended to meet the highest standards of research ethics and scientific integrity and to be comprehensive, covering the full range of issues and concerns – such as dealing with innovative technologies and the novel research possibilities of big data, the challenges of social media research and balancing public interest concerns with cherished rights to privacy. It will be of practical help in guiding interested parties to ways of achieving reliable and trustworthy research. The targeted stakeholders include researchers, reviewers, regulators, research managers and policymakers and, not least, a representative range of research subjects/participants. It will not duplicate existing work – merely guide stakeholders in the direction of established existing good practices.

WHY IS SUCH A PROJECT NECESSARY? Trying to behave ethically and with integrity when conducting research can prove to be complicated given the wide range of codes, guidelines and frameworks. Regulations are diverse and inconsistent, and review practices vary considerably – between countries, institutions, disciplines and professions. As multinational and interdisciplinary research grow, it is vital that the confusion arising out of such disparate approaches should be reduced as far as possible. While there is respect for subsidiarity it is important to offer assistance in making informed and reasoned choices about differences rather than not thinking about them or ignoring them. This points to a difference between social science research and, for example, clinical trials, where a global standard of safety may be desirable to preclude the temptations of 'ethics dumping'.

**THE FOCUS:** Decision takers and policymakers should be seeking evidence to support their work from the range of expertise on offer. Although the concept of 'expertise' has come under significant challenge it is clear that any errors, fraud or corrupt practices by researchers can lead to serious damage to the social, economic and cultural structure of society, as well as impacting the physical environment. But sound, reliable, transparent research, not driven by ideology or subservient to it and undeclared vested interests, produces robust evidence that can benefit social wellbeing and societal progress. It is in the interests of the scientific community to ensure the evidence produced is reliable and trustworthy and ethically generated. It is in the interests of those who make policy to be able to assure the decision takers (and the general public) that evidence has been generated in the best possible way.

### THE CHALLENGE:

Being a 'good' scientist in both the moral and methodological sense is not as easy as it might seem. All researchers have to compromise, make choices and balance potential conflicts and contradictions. Conducting research requires a balance between many political, institutional and professional contradictions and constraints: How should a scientist balance professional responsibilities with obligations to whoever funded their research? How can the safety of both researchers and participants in studies on highly sensitive and controversial political and social issues (such as social unrest, organised crime, or terrorism) and/or in conflict areas or with authoritarian regimes, be assured or at least have their risks minimised? How is the ethic of benefit sharing with participants to be addressed? When should privately commissioned research be shared in the public interest? When should intellectual property be kept private – or owned and sold? Ideology defeats expertise if the evidence is flawed. Responsible researchers cannot allow that to happen. Robust evidence helps to defend expertise against blind ideology. Vested interests,

or those that conflict with the values of scientific integrity, must be challenged by virtuous researchers acting with integrity. The PRO-RES Guidance Framework aims to help them do just that.

### THE UNDERLYING ASSUMPTIONS OF THE PRO-RES FRAMEWORK:

Below are the common elements to be found in existing codes, guidelines and frameworks. These can be regarded as the basic assumptions of the PRO-RES framework:

VALUES and VIRTUES: Throughout most of the existing codes and guidelines there appears a commonly held understanding that the virtuous researcher/scientist holds to certain values. These include a concern to be honest in all the work they do, to cooperate with other scientists in a supportive manner and to show respect for the dignity and diversity of their subjects. They should demonstrate qualities of care, kindness and compassion and the taking of responsibility for all their actions. That includes a responsibility to think through what the consequences of their work might be for society, communities, individuals and even specific groups. At the same time as allowing researchers a reasonable degree of freedom to explore as their discipline dictates, research participants (or subjects, or respondents) must equally be allowed the freedom not to be harmed by research activities. The freedom to conduct scientific research must be matched by enabling those affected by the research the freedom not to be obliged to be party to it. This, in turn, might be balanced by a 'participatory virtue' for research 'subjects' to take part in research that offers mutual benefit to researcher, the researched and the society/community of which they form a part. Nonetheless, engaging in certain research acts and situations requires considerable courage on the part of researchers and the those being researched, this too is considered a virtue of responsible scientific practice. These values and virtues need to be supported by the cultures and structures of the institutions in which the researchers work.

**VICES:** The primary concerns of research integrity are framed as the corollary of these virtues. These include incompetence, indolence, malicious deceit, the misrepresentation of facts and findings, fraudulent use of data, plagiarism and other forms of corrupt practices – such as harassment, bullying and/or nepotism. Stigmatising or prejudicial language, distortions, or data-gathering biases such as racism/ethnocentrism and sexism are reproved. So too are practices *intended* to entrench social exclusion or marginalise specific social categories – such as those with a disability or the aged or infirm or ethnic groups. The failure to credit or acknowledge the value of all contributions to a research activity is also to be considered a vice.

**PRINCIPLES:** In combining the values and virtues to be sought and the vices to be avoided, most codes and guidelines advocate the applications of certain principles. In order to bear responsibility scientists must participate in open and democratic processes and be accountable for their actions. They need to operate in a collaborative and collegial manner, apply their data collection, findings and research outcomes proportionately, justly and fairly. The larger community – both public and professional – should benefit from and not be harmed by their activities. What constitutes 'the public' and consequently the 'public good' should not remain unexamined. For example, the business or commercial community and the armed forces should also be included in our understanding of 'the public'. The involvement of the subjects of research should, as far as possible, be on a voluntary basis – none should be forced to participate nor bear the consequences of a research scientist's actions without their informed agreement – though specific principles are necessary to cover those observed in public settings and covert observations of behaviour or phenomena that could not be studied in any other way and that is necessary for societal benefit. Both researchers and researched need to be accorded a degree of autonomy or independence – both in terms of how the ongoing research is conducted and whether they choose to continue to participate. Reliable research will depend upon a just and equitable selection and treatment of subjects, or participants, or

respondents. The diversity of research subjects/participants must be accounted for and their participation in or departure from a research study facilitated.

**STANDARDS:** The standards to ensure that research is conducted ethically and with integrity are contained with sets of rules for good governance. These will include standard operating procedures for the evaluation of projects proposals and the system of ethics oversight – the form and content of research ethics review committees or any other review, monitoring or ethics approval process. Equally important are the regulated means for safeguarding scientists, their subjects, their findings and their intellectual property, whether in the form of patents or publications. Sanctions must be available for those researchers that fail to fulfil their obligations without good reason. Results must be auditable and provision made for honest and constructive critique of malpractice – such as whistleblowing. Standards for due process must include means for resolving conflicts of interest.

#### Note on Values and Virtues

We underline the need to be as succinct and pragmatic as possible given the nature of our target audience. We felt the need was to indicate their use to non-technical experts in research, policy advice and policymaking.

We had no intention to enter these terms as in a formal dictionary and so did not feel the need to attempt to reconcile the differences between a values- and a virtues-based approach for present purposes.

We recognise how important it is to be clear on how we recommend use of the relevant terms. We did investigate other glossaries in related projects and found them less comprehensive and detailed in many cases.

More importantly the glossary was never intended to be 'fixed' it is meant to encourage debate, dialogue and a move towards a consensus of understanding that can be shared across the extremely varied needs of researchers in the non-medical sciences. Thus any further nuances that need including will be done so via the interaction with those who engage with the Framework.

Thus our definitions are intended to assist ethical research activity and those seeking to use it for policymaking purposes. To fully 'contextualise' our intent here, all the terms in the glossary must be of pragmatic use to practising researchers and so have clear impact on advisors and policymakers.

In sum the principles underpinning the statements in the Accord and the Framework are driven by pragmatism, in order to provide us with the necessary flexibility when addressing the diverse audiences that we intend to reach.

### TO BE CLEAR ABOUT THE TERMS AND CONCEPTS WE ARE USING LOOK AT: 'LINK TO GLOSSARY OF TERMS' AND WE NEED TO BE CLEAR ABOUT WHAT WE MEAN BY RESEARCH MISCONDUCT: LINK TO 'MISCONDUCT'.

WE ADVISE THAT YOU RETURN TO CHECK ON THESE TERMS AS YOU INTERROGATE THE FRAMEWORK.

NOW ENTER THE FRAMEWORK BY CHOOSING YOUR ROUTE: (LINK TO 'ROUTES')...

### **GLOSSARY OF TERMS**

**DEFINITIONS OF TERMS AND CONCEPTS:** It is essential that the understanding of terms and concepts related to research ethics and scientific integrity is shared across all communities of interest. The Framework includes a glossary of terms and concepts drawing upon the existing literature and pointing to the key dilemmas to be addressed. The terms and concepts are listed in alphabetical order for ease of access – this does not imply any other form of priority. Note these terms might have different meaning or applications in different contexts. Their use here is in relation to the maintenance of ethical research practices. The definitions we supply are based on a lengthy consensus process agreement. Their use is based first on consensus amongst PRO-RES consortium partners and then on agreement with a representative sample of stakeholders.

### GLOSSARY

Academic Freedom	Refers to freedom for individuals within the academy, rather
	than the autonomy of academic institutions within society,
	although the two are linked. While the meaning and
	boundaries of the term are contested, it requires individual
	academics to operate with freedom (and the responsibilities)
	to determine a range of matters in relation to teaching,
	research, self-governance, and with the protection of
	guarantees of continuing employment. In exercising these
	freedoms, academics have a responsibility to follow the ethical
	and integrity norms established by their peer associations,
	institutions and regulators, though again these are disputed.
	The European universities' Magna Charta Universitatum
	declares: 'Freedom in research and training is the fundamental
	principle of university life, and governments and universities,
	each as far as in them lies, must ensure respect for this
	fundamental requirement' (European Universities Association,
	1988, 1). The European Charter for Researchers recognises
	research freedom as 'the freedom of thought and expression,
	and the freedom to identify methods by which problems are
	solved, according to recognised ethical principles and
	practices', albeit within institutional, financial and legal
	constraints. This freedom is seen as central to the role of the
	university as a protected space where a search for innovation
	and scientific truth can be carried out without fearing the
	impact of external interests or hierarchies. It is, however,

	conditional upon the acceptance of a responsibility to engage in that search and to exclude those external concerns (Dingwall 2016).
Accountability	Accountability means taking responsibility for your actions rather than trying to attribute responsibility (or blame) elsewhere. This involves being able to explain the reasons behind your actions when necessary, and being prepared to discuss your actions and their consequences. This implies a willingness to accept and act on criticism of your actions where that is justified. Accountability is a central principle of Indigenous research axiology [see also <i>Axiology</i> ].
Acknowledge (and failure to)	Give appropriate credit to someone for their ideas or effort that have contributed to a project (or fail to do so). [See also <i>Authorship.</i> ] 'Appropriate credit' varies by discipline. For example, in psychology, people who have contributed to a research project may be listed as authors of an article about the findings even if they have done no work on the article itself. In social sciences, authors are generally listed in approximate order of amount of work done on the article, while in economics they are listed in alphabetical order (which has been shown to disadvantage female co-authors). There is considerable <u>anecdotal evidence of doctoral supervisors failing</u> to acknowledge the work of their students.
Aftercare	This refers to researchers' responsibilities after the end of a project. It is not easy to define the end of a research project: is it when the funding has all been spent, or when the last meeting has been held, or the last output published? Whenever the end point is, researchers' responsibilities continue (Kara 2018). We are still responsible for participants' welfare, and for helping them when necessary, such as when a participant needs amendment to or removal of a digitally published output years or decades later. We retain responsibility for ensuring that our data is stored appropriately and that, as far as possible, our findings are used [see also <i>Application</i> ]. And we are always responsible for our own wellbeing as researchers.
Anonymity	Granting to participants or others the right to have their name and other identifying details withheld from third parties. Committees or boards that grant ethical approval usually require researchers to maintain participants' anonymity. However, this is not always ethical in itself. For example, <u>Kristen Perry worked with Sudanese refugees in America</u> and found they became upset and angry when she told them she would use pseudonyms for them in her publications. On further investigation, she found that the repressive majority

	regime in Sudan would force name changes on people from the minority (Perry 2011). While anonymity is appropriate in many cases, some research participants have compelling reasons for wanting to be named.
Application (of findings)	Putting research findings to use in professional or other practice. This is generally regarded as ethical because it maximises use of the resources expended on conducting the research. However, it is also necessary to ensure that research findings are applied in ethical ways.
Assent	The agreement of someone not deemed able to give consent due to, for example, youth or cognitive impairment [see also <i>Consent</i> ]. This contains the implication that a parent or a carer will always be better able to give consent than a child or a patient. However, that may not be the case if the parent or carer's own judgement is impaired due to, for example, substance misuse, side-effects of prescription drugs, or severe mental illness (Bray 2014). Also, young children, those with cognitive impairment, and others, may be able to give consent if they are asked in a way that they can understand (Alderson and Morrow 2011).
Audit	A type of research that aims to reveal the level of wellbeing of an institution, community, or other entity through examination of factors in play such as resources, assets, and expenses. <u>Although this stance has been contested</u> , audit is generally not thought to require ethics regulation because it is being conducted for internal organizational processes of accountability or quality assurance. However, it presents similar ethical issues to other types of research and these should be taken into account. Additional ethical problems can arise when audit moves from a tool of measurement to a tool of manipulation, such as in the 'audit culture' in which audit becomes 'a central organizing principle in the governance and management of human conduct' (Shore 2008).
Authorship	The International Committee of Medical Journal Editors recommended four conditions for authorship (2013, s.II.2): Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND Drafting the work or revising it critically for important intellectual content; AND Final approval of the version to be published; AND Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

	These conditions can be breached either because someone with insignificant involvement has been added (gift, honorary or prestige authorship) or because those who made significant contributions have been omitted (ghost authorship). In the case of ghost authorship, this might be because a junior staff member's labour is being exploited, or because the real author seeks to conceal his or her responsibility (for example, when a pharmaceutical company funds a trial and attributes the results to an apparently independent researcher). (See also <i>Acknowledge</i> )
Autonomy	Independent, self-governing. The opposite of collectivity. As a principle, autonomy is in general highly valued in European and other Western countries, while collectivity is valued more highly in the global South (Kara 2018). The implication of this for ethical research practice in Euro-Western settings is that the autonomy of participants and other stakeholders should be respected. In other settings, researchers may need to make a judgement about the implications of respecting collective values, as expressed by community leaders, on hearing views from other members, who may be marginalized or disadvantaged by current arrangements. (See also <i>Principlism</i> )
Axiology	The branch of philosophy that includes ethics. Axiology 'refers to the analysis of values to better understand their meanings, characteristics, their purpose, their acceptance as true knowledge, and their influence on people's daily experiences. It is the branch of philosophy that deals with the nature of ethics, aesthetics, and religion, where religion encompasses spirituality (Guba & Lincoln, 2005), and their role in the construction of knowledge.' (Chilisa 2012) (See also <i>Accountability</i> )
Beneficence	Acting to create benefit. In research, influenced by biomedical research, this is generally seen as benefit for participants. However, creating benefit is not always straightforward. There is almost always some risk of harm to research participants, however hard researchers may work to minimise or mitigate that risk. Also, research participation that does not benefit an individual may benefit their community through learning generated by the research. <u>Researchers need to assess the</u> <u>potential for beneficence to individual participants and other</u> <u>stakeholders, to their communities, and to wider societies and</u> <u>cultures. (See also Principlism)</u>
Bias	"A bias is a tendency, inclination, or prejudice toward or against something or someone." Biases can be positive, such as a bias towards caring for others or away from crime. However, biases tend to be based on assumptions rather than evidence

	or logical thought. This means that bias can lead to poor judgement and discriminatory action. A combination of individual biases and other factors can lead to structural biases, such as the well-known publication bias towards positive research findings. There are two main ways in which individual researchers can tackle bias: <i>Debiasing</i> and <i>Reflexivity</i> .
Bullying	Bullying is generally defined for research purposes as the frequent, persistent and hostile harassment or intimidation of someone less powerful (Samnani and Singh 2012). However, definitions of bullying can vary between cultures. (Boynton 2017). Bullying is prevalent in workplaces, including higher education institutions (Boynton 2017), with almost 95% of employees having some interaction with workplace bullying over a five-year period (Fox and Stallworth 2005). People are more likely to be victims of bullying if they have a disability, are from a minority ethnic background, or are LGBTIQ+ (Boynton 2017).Bullying should be distinguished from the clear expression of legitimate and relevant concerns about work performance. 'Academic Freedom' claims can result in any attempt to ensure accountability for time and resources being defined as 'bullying'.
Care	Care means having concern for someone's wellbeing; expressing that concern; taking steps to help someone maintain or improve their wellbeing. In relation to ethics, the 'ethics of care' refers to making sure all participants and other stakeholders are cared for during the research process and beyond. This is often set in opposition to ethics of justice, which operates by aiming to treat everyone equally, while ethics of care implies treating everyone according to their needs. However, Edwards and Mauthner (2012) drawing on the work of Sevenhuijsen (1998) have demonstrated that ethics of justice and ethics of care can be seen as part of a single process.
Cognitive bias	This is a particular kind of <i>bias</i> denoting automatic and replicable errors in thinking (Kara 2018). Over 100 kinds of cognitive bias have been defined, some of which are relevant to researchers. Examples include: sameness error, i.e. thinking things are the same (e.g. for women and for men) when they're not (Chilisa 2012); Berkson's paradox, i.e. two values appear to have a positive correlation when in fact they are negatively correlated; belief bias, i.e. giving more credence to one's personal beliefs than to facts, data, or findings. Cognitive biases can be counteracted by <i>Debiasing</i> .
Collaboration	A unifying activity of working with another or others to produce something together for mutual and wider benefit in

	which collaborators are united in a common enterprise and use a common identity to achieve shared goals. Collaboration among researchers usually involves conceptualisation of aims and methods, management and communication, accountability, outcomes and authorship. These are spelled out in more detail in the <u>Montreal Statement</u> (See also <i>Cooperation</i> )
Compassion	Often referred to as a virtue, a deep awareness of, concern and sensitivity to the suffering or misfortune of another or others, and a motivation to help them. The suffering or misfortune is of a kind that can be readily understood and identified by the person who experiences compassion. <u>(Strauss 2016)</u> . Beyond interest in compassion as the subject of research, its relevance to research may lie in the effects on researchers who themselves experience compassion. As a result, they may be exposed to the risks of compassion fatigue (Newell 2010) and to losing clarity about their researcher role in a project.
Conflict of interest	Conflicts of interests occur when personal, financial, political and academic concerns co-exist and the potential exists for one interest to be illegitimately favoured over another that has equal or even greater legitimacy, in a way that might make other reasonable people feel misled or deceived. Conflicts of interest reside in a situation not in behaviour and may arise even when there has not been research misconduct. Researchers caught in a conflict of interest risk appearing negligent, incompetent or deceptive. There is little clear guidance of when to declare and how to manage competing interests. Conflicts of interest also exist at institutional level.
Confidentiality	A legal and ethical obligation imposed on the recipient of information provided by another person (the provider) not to use that information for any purpose other than that for which the information was provided. The obligation can arise from a relationship or from a contract and applies to all information that is provided and that is not publicly available, whether or not the information identifies the provider. The relationships that are recognised to involve the obligation are typically between professionals and clients or patients. Although it is not settled whether the relationship between research and research participants, of itself, involves the same obligation, researchers commonly define the degree of confidentiality that will be offered as a term of consent for participation. Researchers need to be aware of the possibilities not only of external confidentiality (as described in this entry) but also of internal confidentiality, that is, the inadvertent disclosure of information among research participants.

	The obligation can be superseded by the need to use the information to serve a public interest, such as the protection of children, prevention of the spread of infectious disease, the conduct of court proceedings and the investigation of serious criminal offences. In such circumstances, researchers can be compelled to disclose information that was collected in confidence. (See also <i>Privacy; Public Interests; Transparency</i> )
Consent	Agreement to take part in research. This should be based on an understanding of the research project and its aims [see also <i>Informed Consent</i> and <i>Free, Prior and Informed Consent</i> ]. In theory consent should be freely given or withheld as the potential participant prefers. In practice some research, such as national census research in some countries, is mandatory and those who do not participate may be punished (Kara 2018). The granting of consent is often treated as an event, where in fact it is more of a process that is negotiated and renegotiated as research progresses. Indeed, in some cases renegotiation is essential, such as in research with people with cognitive impairment or in longitudinal research.
Cooperation	A connective activity among individuals or groups whose contributions are complementary, where participants are all working to achieve the goal for their own benefit. This might occur, for example, by dividing portions of a research project among contributors for each to complete the assigned portion of the project individually. Those who cooperate remain separately identifiable, may commence and end at different times and their contributions do not have a shared identity. (See also <i>Collaboration</i> )
Corruption	Although corruption is the focus of international policies and strategies for its elimination, such as the <u>UN Convention</u> and the <u>European</u> Commission Policy, it is a complex concept and difficult to define with precision. In practice, corruption can take the form of bribery, nepotism or misappropriation. Common elements of conceptual definitions include the exercise of a public duty for a benefit provided to the duty holder by a person who gains a reciprocal benefit from the wrongful exercise of the duty of that duty holder; dishonest or fraudulent conduct by those in power, typically involving bribery. Other definitions focus on the abuse of a trust, generally involving public power, for private benefit usually in the form of money or on the exclusion of an opportunity to participate in open, competitive, and fair political and economic processes (Johnston, 1996). Another recurrent

	element is that corruption is consciously unfair or discriminatory and permits persons holding power to decide without competition, and through covert considerations, who gets what he or she wants or needs (Rotberg, 2017).
	Corruption can be equated with injustice. If justice is what is expected from political leaders and governments, then corruption can mean unjust actions committed by them. This applies with most force to public goods: the central notion of which is that they are to be managed and distributed by principles different from those applying to the distribution of private goods which can be distributed according to the wishes of those who manage them. Distributing public goods in similar ways as private goods is seen as corruption (Rothstein, 2017).
	In the research context, using these approaches to definition, any public process for the determination of funding agencies' research subject priorities, the funding of research or the scientific or ethical approval of research can be vulnerable to corruption.
	Individual and teams of researchers may also be bribed to amend or distort their research. Such conduct could be described as corrupt where the briber benefits reciprocally and if it is accepted that the responsible conduct of research is a public good. (See also <i>Conflict of Interest</i> .)
Debiasing	Processes that aim to identify and remove biases that are likely to affect the way that research is formulated, conducted and reported. For researchers, de-biasing involves accepting, detecting, analysing and changing personal biases in their formulation and conduct of research. For participants in research, de-biasing involves detecting, analysing and adopting strategies to minimise the effects of biases in participants that may lead to distortions in recruitment and participation. Such processes are only ever partially successful. Some cognitive biases (see above) can themselves act as impediments to debiasing (Kara 2018) (See also <i>Bias</i> )
Deceit	The action or practice of wilfully or recklessly concealing or misrepresenting the truth or material facts with an intent to mislead. In research, knowingly concealing facts that are material to the approval of research, especially as to relevant prior research, in seeking research funding or ethics approval or knowingly concealing or misrepresenting relevant risks from potential participants could all be described as deceit.

Democracy	A belief in freedom and equality between people or a system of government based on this belief in which power is either held by elected representatives or directly by the people themselves. Democracy can be an important contextual factor for the conduct of research. The 2012 <u>Resolution</u> of the Brazilian National Council on Health links the national constitution to the conduct of research. Researchers have commented on the ethical dilemmas in conducting research in less democratic countries. (Wackenhut 2018)
Dignity	The intrinsic importance and value that a person has, that warrants respect from other people and for themselves, having a state or quality of being worthy of honour or respect. This short definition reflects the two historical and conceptual origins: the theological idea of inherent human value and the humanist idea of the respect owed to a rational being. (See Rosen, pp. 1-62). In research, these elements are also reflected. The inherent value of human beings informs the obligation of researchers to minimise risks to research participants while the respect owed to rational beings is the basis for requirements about consent to participation. In her rejection of the value of the concept, <u>Macklin</u> argues that it means no more than respect for human beings. This position, by focussing on only one of the origins of the term, ignores the theological origin that gives the term a useful meaning of inherent human value that is relevant to assessing the risks that research may pose for participants and affect other humans.
Dissemination	The acts and processes of distributing and sharing widely results, outcomes, findings and information gained through research, in order to contribute to knowledge or practice or to serve a public good. Dissemination can be in the form of publication in peer-reviewed journals or books, conference presentations, commissioned reviews for public bodies, other forms of media or creative works and will accord with the research discipline or subject. Risks to research stakeholders or populations from dissemination of research outcomes could justify withholding, postponing or limiting dissemination only if those risks outweigh the public benefit of dissemination.
Diversity	The motto of the European Union, "united in diversity" signifies how Europeans from many different cultures, traditions and languages have come together to work for peace and prosperity. It is the leading example of the central sense of the term as the situation resulting from many different types of things or people being included in a whole. The EU exemplifies diversity of individuals representing more than one national origin, religion or language.

	The term applies equally to the inclusion of people from different socio-economic strata or the fact that there are many different ideas of opinions about something. Where the aims of a research project include drawing conclusions from a sample that will be relevant for other populations, evidence of the extent and nature of diversity in the sample population will be an important consideration.
	Where diversity is required to meet the aims of research, ensuring the necessary degree of diversity in research participant populations will require recognition that traditional inclusion criteria have often excluded children, women, women of child-bearing age, prisoners, undocumented immigrants and people with physical, intellectual or emotional disabilities.
	Achieving diversity in Europe-wide research will also require attention to avoiding imbalances in recruitment that privilege some regions and/or disadvantage others.
	Diversity is not essential where it is not relevant to the research design, as in case control studies, or where the focus is on problems that only affect specific population groups like thalassemia or sickle cell anaemia.
Dual use	Research that, based on current understanding, can reasonably be anticipated to provide knowledge, information, products, or technologies that could be used to present a threat to public health and safety, plants, animals, the natural environment, or national security. Although more commonly associated with technological or medical research, the concept has been shown to apply to <u>life science</u> and social science research. A related example involving the placement of anthropologists with troops in the field was the controversial human terrain system conducted by the United States Army (Gonzalez2018). An alternative view on dual use and the work of social scientists alongside the military is offered by Durkin (2015). See also the <u>European</u> guidance note.
Due process	A citizen's fair treatment in conformity with the principles. rules and processes of a democratic state's legal system, including the right to a hearing before administrative action, the right of access to essential facts; the right to legal advice, the duty of the administrative decision-makers to give reasons for decisions and to indicate the possibilities for legal challenge to decisions. More narrowly, the course of formal proceedings (such as legal proceedings) that is carried out regularly and in accordance

	with established rules and principles, the judicial requirement that enacted laws may not contain provisions that result in the unfair, arbitrary, or unreasonable treatment of an individual. In research, due process can refer to following and applying the processes of application and decision-making in distributing research grants or in granting scientific and ethics approval for research projects or in the processes for identifying and investigating research misconduct.
Duplicate and redundant publication	Publishing two or more papers that share exactly the same hypothesis or question, data, discussion and conclusions, or present little or no new material (see self-plagiarism). In the social sciences, it may be appropriate to publish similar materials in journals with different readerships so that findings receive appropriate dissemination. This is particularly important when social scientists are working within multidisciplinary teams, seeking to reach professional audiences through publication in professional journals, or are communicating with a new audience through another language. Such duplication should be acknowledged through relevant self-citation (see <i>Self-citation</i> ).
Editorial misconduct	Editors have responsibility for running their review processes fairly and reaching publication decisions impartially. This requires them to declare their own conflicts of interest and manage the conflicts of others. Editorial misconduct may include: failing to use appropriate review processes where necessary, or misrepresenting whether a paper has been reviewed; unfairly favouring their own publications or those of colleagues, students or former students or family; failing to notify the relevant institutions or correct the record once evidence of research misconduct becomes apparent. Editors may also engage in misconduct if they coerce or allow the coercion of authors to add citations that reference the editor, the journal or a cartel of other journals; stack editorials with citations to that journal; swap citations within a cartel of journals.
Equity	The word has a number of meanings. In the research context, it usually refers to arrangements or distributions that are proportional to contribution or desert and, in these senses, fair. An equitable arrangement may also treat individuals equally, where their contributions or deserts are equal, but equity is more often equated with fairness than equality. In research, ordering the list of authors in proportion to the extent or significance of their contribution would be an equitable treatment of members of a research team.

Eudaimonia	The state and practices of living in an ideal situation of being healthy, happy, and prosperous, arising from and maintained by actions that result in that state of individual well-being. This definition attempts to capture the overlapping senses of the word when originally used by Aristotle. That word referred as much to the practices of life as to the ideal state of living. While this is sometimes proposed as a goal for all research, that it should contribute towards the achievement of an ideal condition for humanity, it is not clear that there is, or could be, sufficient agreement on what the key terms mean when they have to be translated from, abstractions into actual living conditions.
Exclusion criteria	'a set of predefined definitions that is used to identify subjects who will not be included or who will have to withdraw from a research study after being included' (Salkind, 2010). Inclusion and exclusion criteria are used to create the selection and eligibility criteria when used to determine who can participate in a research project. Inclusion and exclusion criteria should be based on both methodological and ethical grounds. Poor choices of inclusion and exclusion criteria may unfairly distribute the harms and benefits of research, leading to exploitation of vulnerable populations or the inability for the benefits of research to be applied to particular populations. Similar issues may arise in literature or systematic reviews where the choices of exclusion and inclusion criteria can inappropriately shape the results. Unexamined assumptions about a 'hierarchy of methods' are often responsible for this, rather than considering the fit between problems and the methods by which they might be investigated. (See <i>Inclusion</i> <i>Criteria</i> )
Fabrication	<ul> <li>'making up data or results and recording or reporting them'(US</li> <li>Federal Policy on Research Misconduct, 2000) Fabricated data</li> <li>do not exist at all but have been invented or created by the</li> <li>researcher.</li> <li>[see Falsification].</li> </ul>
Facilitation	UK Medical Research Council used to include 'facilitating of misconduct by collusion in, or concealment of, such actions by others' in its definition of scientific misconduct (1997). This is still part of the definition adopted in some other parts of the world, it places some responsibility on researchers to police the activities of their colleagues. The implications of such intervention will depend on the legal and institutional protections afforded whistleblowers, and value of reporting misconduct will depend on the actions of those to whom wrongdoing is reported (See <i>Whistleblowers</i> ).

Falsification	'manipulating research materials, equipment, or processes, or changing or omitting data or results such that the research is not accurately represented in the research record' (US Federal Policy on Research Misconduct, 2000 and European Code of Conduct for Research Integrity). Images may constitute data and so falsification can include inappropriate image manipulation and duplication. Falsified data do exist but have deliberately been altered. [See <i>Fabrication</i> ]. Fraud is 'a deliberate act of deception intended for personal
	gain or to cause a loss to another party' (European Anti-Fraud Office). Researchers may commit fraud – sometimes in the form of fabrication or falsification – in order to gain grants or jobs. A significant proportion of retractions of journal articles are the result of fraud, or suspected fraud, by the author or corporate interests. In biomedicine and other disciplines, fraud can distort the evidence base and lead to harm to patients. In engineering, construction and materials, fraud may lead to serious technological failures that harm both individuals and communities.
Free, prior and informed consent (FPIC)	Binding and non-binding international developments in law relating to Indigenous rights led to the International Labour Organization's Convention concerning Indigenous and Tribal Peoples in Independent Countries (1989) and the United Nations Declaration on the Rights of Indigenous Peoples (2007) These require that, in situations such as the extraction of natural resources from or construction on Indigenous lands, the free, prior and informed consent (FPIC) of Indigenous peoples must be sought. The UN Permanent Forum on Indigenous Issues explained FPIC as consent: involving no coercion, intimidation or manipulation; being sought sufficiently in advance of any authorization or commencement of activities and respecting time requirements of indigenous consultation/consensus processes; grounded in information being provided that covers the nature, size, pace, reversibility, scope, purpose, duration, location, impact, personnel involved and procedures of any proposed project or activity; and based on consultation and participation. Some countries (Bolivia, Colombia, Ecuador and Peru), have legislated or regulated to require that the right of Indigenous peoples to offer FPIC be respected in a range of matters. In relation to research, this is reflected in national guidance for health-related research in Philippines, Taiwan.
Governance	The policies, rules, processes and behaviour that affect how powers are exercised. In the EU, good governance is underpinned by: openness, participation, accountability,

	effectiveness and coherence (2001 EC White Paper on European Governance). A 2015 report for the EC argued that good sectoral governance in research and innovation required 'openness and participation through a network approach rather than a linear, top-down chain of command'. This may be in tension with the common legal expectation that a controlling mind can be identified and held personally accountable for the actions of an organization.
Harm	Joel Feinberg (1984) defined harm as the 'defeating of an interest', where the interests of an individual are defined as 'the range of things in which that individual has a stake'. Although the influence of bioethics means harm is most often understood in physical terms, it also includes psychological, social, economic, reputational, legal and environmental damage. In social science research, harm is generally more likely to involve psychological distress, discomfort, social disadvantage, stigma, invasion of privacy or infringement of rights than physical injury.
Honesty	The European Code of Conduct for Research Integrity identifies honesty 'in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way' as one of the fundamental principles that underpins research integrity. The earlier 2011 edition pointed to the need for honesty in 'presenting research goals and intentions', and in making 'justifiable claims with respect to possible applications of research results'. Research integrity codes also place responsibility on institutions to ensure that all participants in misconduct investigation act honestly. Honesty may also relate to the use of any financial or other organizational resources granted, contracted or allocated to a research project for the benefit of that project rather than for any direct personal gain.
Inclusion criteria	'a set of predefined characteristics used to identify subjects who will be included in a research study' (Salkind, 2010). Inclusion and exclusion criteria are used to create the selection and eligibility criteria when used to determine who can participate in a research project. Inclusion and exclusion criteria should be based on both methodological and ethical grounds. Poor choices of inclusion and exclusion criteria may unfairly distribute the harms and benefits of research, leading to exploitation of vulnerable populations or making it impossible for the benefits of research to be applied to particular populations. Similar issues may arise in literature or systematic reviews where the choices of exclusion and inclusion criteria can inappropriately shape the results. Unexamined assumptions about a 'hierarchy of methods' are

	often responsible for this, rather than considering the fit
	between problems and the methods by which they might be
	investigated. (See Exclusion Criteria)
Independence of Research	ALLEA's European Code of Conduct for Research Integrity argues that research should ideally develop 'independently of pressure from commissioning parties and from ideological, economic or political interests'. For research to be independent, decisions about research questions, methodologies, analyses, results, conclusions and dissemination that is not influenced by the views of funders (public or private) or host institutions. The ability to assert independence may depend on the existence of a diversity of funding sources, collaborators, institutional hosts, sources of data, methodological and theoretical approaches. Inevitably, the degree of independence of research falls along a continuum. This reflects the terms on which the research is conducted rather than the source of funding. It should not be assumed that public or NGO funding is necessarily independent or corporate funding is necessarily compromised.[see <i>Conflict</i> <i>of Interest</i> ].
Indolence	Some literature points to structural causes for research misconduct. In this explanation, fabrication, falsification and plagiarism become shortcuts to meeting unrealistic workloads or expectations. Other commentators point to moral failings, including indolence or laziness that might grow from frustration or boredom (Macfarlane, 2009). It may be hard to distinguish moral failings from lack of engagement due to poor design or management that leaves researchers indifferent to the process and outcome of the project (Roth 1966).
Informed consent	Informed consent implies that participants need to have substantial understanding of, and agree voluntarily to, the nature of the research and their role within it. Participants need to have the capacity to consent. Consent is generally recorded, though written agreement may not be necessary or appropriate. In some circumstances, some guidelines allow for the deception of participants, or for research to occur without consent (where there is negligible risk and observation occurs in a public space where there is no reasonable expectation of privacy; where there is public interest in allowing the research and there is no other way of conducting it; where a subject is unable to consent).
Justice	Different conceptions of justice exist and there is disagreement about how they might be applied to research. Justice is one of the four principles introduced in the Belmont Report. Research ethics guidelines tend to refer to distributive and procedural

	ideas of justice, pointing to the need for benefits and burdens of research to be distributed fairly and for participants to receive fair treatment in their recruitment and depiction and in various other stages of the research process. However, these arrangements might be regarded as exploitative in that the benefits to the participating individuals and communities would not be commensurate to either the risks placed on those communities or the benefits that might accrue to the researchers or the sponsors of the work. In addition, there are other more radical understandings of justice that, for example, critique the gendered or racialized nature of traditional approaches and advocate, among other things, more social, global or Indigenous approaches. (See also <i>Principlism</i> )
Kindness Ethics	Developed within Confucian ethics as a virtue or character trait rather than an ethics of action. One of the five elements of Confucian perfect virtue (in the Analects). Encompasses a disposition of decency and good sense, and caring for the well- being of all life (rather than being anthropocentric), including one's own.
Maleficence	Refers to causing harms or seeking to cause harms; can imply 'evil' intent but may also be used where the harm is not intentional. In ethics, 'non-maleficence' is commonly paired with beneficence as a core guiding principle. (See also <i>Principlism</i> )
Malfeasance	Typically used to refer to intentional wrong-doing, especially in a corporate context.
Misrepresentation	Where falsities are asserted as facts, where other people's views, utterances or actions are reported inaccurately or falsely, or where research findings are not truthfully published or otherwise reported. Can also refer to spreading false information about persons, groups, organisations.
Misuse	If research data or findings are used for purposes that were not part of the initial research design and are associated with actual or potential harm, this counts as misuse. A topical example would be the use of data to influence voting behaviour which was gathered via social media purportedly to solely feedback a 'personality profile' to completers. (See also <i>Dual Use</i> )
Nepotism	Using a privileged position to unfairly favour individual research colleagues, collaborators or relatives over other persons in giving access to resources or other benefits, such as employment opportunities.
Non-maleficence	Researchers are normally expected to minimize risks of harm or discomfort to participants (See also <i>Harm; Principlism</i> ).
Obligations	Explicit or implicit requirements for the conduct of persons and organizations involved in research towards participants,

	funders etc., that are established by ethics principles, codes or
	guidelines, by specific conditions drawn up as part of a
	research design or by general law.
Operating procedures	Detailed specifications of processes to be followed by bodies
	such as research ethics committees in dealing with matters
	such as the reviewing of applications, the hearing of appeals
	against decisions or responding to complaints.
Plagiarism	Presenting other people's work or ideas as one's own, for
C C	example by including text from another author in one's own
	writing without attribution, is plagiarism. Self-plagiarism, the
	unacknowledged re-use by an author of text written for one
	publication in a subsequent other publication may also be
	ethically unsound, dependent on context. (See also Duplicate
	and Redundant Publication; Self-plagiarism).
Principles	Statements of principle seek to promote consistency across
·	broad ranges of actions or the evaluation of actions, in
	alignment with specific values.
Principlism	An approach to ethics in biomedicine associated particularly
·	with the US philosophers Tom Beauchamp and James
	Childress. It argues that ethical judgements can be made by
	reference to four principles: Autonomy; Beneficence; Non-
	maleficence; and Justice. While these principles can be applied
	more widely (e.g Murphy and Dingwall 2001), there has been
	concern that they function too much like a checklist and, in
	particular, that their US origins mean that Autonomy tends to
	trump Justice. (see also Autonomy; Beneficence; Non-
	maleficence; Justice.
Privacy	A concept recognising that persons have sensitivities regarding
	information about themselves (including imagery) which they
	would not wish to be made public or shared widely. Respect for
	privacy is a widely held ethics principle and is a basis for
	establishing confidentiality protocols in research as well as
	limits on forms of data gathering.
Proportionality	Commonly used in research ethics discourse to refer to taking
	account of the risk level of a research design in deciding the
	scale of ethics review and governance, or adjusting mitigation,
	consent protocols or other research practices to the level of
	risk foreseen.
Publication ethics	The principles, practices and policies that ensure published
	work can be trusted as a reliable source. The Committee on
	Publication Ethics (COPE) has developed a taxonomy of
	publication ethics issues. These issues may occur at any stage
	of the publication lifecycle from author through editor to
	publisher. They might also arise from the work of reviewers,
	translators and funders. Some relate to a particular role in the

	process, such as ghost and guest <i>authorship</i> , <i>fabrication</i> , <i>falsification</i> and <i>plagiarism</i> or predatory publishing. Others, such as <i>conflicts of interest</i> , may occur at several stages. Issues identified in publication ethics may lead to correction of the published record as well as investigation of the circumstances under which the issue arose. Changes in the publishing industry (Open Access, pre-print publishing and post-publication review) will necessitate ethical responses.
Quality	Property or attribute. Typically used in research ethics to refer to 'quality' of research design and implementation as measured against criteria such as scientific soundness, meaningfulness of research questions, significance of findings or level of ethical sensitivity.
Questionable Research Practices	Many research integrity codes and statements developed outside the United States have extended their definition of research misconduct well beyond <i>fabrication</i> , <i>falsification</i> and <i>plagiarism</i> to include other matters such as: undisclosed <i>duplicate publication; misrepresentation</i> of data, interests, qualifications and involvement in <i>authorship</i> ; mismanagement of data; breaches of duties of care including improper conduct in peer review; unethically interfering with other people's research; and, poor institutional policies, procedures and practices to foster research integrity and improper responses to allegations of misconduct, including retaliation against <i>whistle-blowers</i> . This extended range of issues is sometimes termed 'questionable research practices' or, more accurately, 'detrimental' research misconduct are being sought for matters such as harassment, bullying and discrimination within research teams (See also <i>Bullying; Sexual harassment</i> ).
Racism	Using the scientifically unsound concept of 'race' to generalise about and stigmatise specific groups, typically on the spurious criteria such as country of origin, skin colour, presumed religious affiliation or ethnic practices. Also acting towards colleagues, peers or students on the basis of such assumptions.
Rapport	Establishment of a congenial, trusting relationship with another individual which involves mutual understanding. An important basis for effective participant interviewing in research.
Reflectivity	The act of applying critical evaluative thinking to one's behaviour. In research, seeking to become aware of potential personal biases or shortcomings in all stages and aspects of research.
Reflexivity	In research, reflexivity refers to a researcher applying to themselves the same critical frame, methods or analyses that

example, a discourse analyst might reflexively analyse their own discursive treatment of their data. Commonly erroneously used interchangeably with <i>reflectivity</i> ReliabilityA valued property of research methods and findings such that they can be relied upon. For example a method that demonstrably produces comparable, consistent data when
own discursive treatment of their data. Commonly erroneously used interchangeably with <i>reflectivity</i> Reliability       A valued property of research methods and findings such that they can be relied upon. For example a method that demonstrably produces comparable, consistent data when
used interchangeably with reflectivity         Reliability       A valued property of research methods and findings such that they can be relied upon. For example a method that demonstrably produces comparable, consistent data when
Reliability       A valued property of research methods and findings such that         they can be relied upon. For example a method that       demonstrably produces comparable, consistent data when
they can be relied upon. For example a method that demonstrably produces comparable, consistent data when
demonstrably produces comparable, consistent data when
used by different researchers, or when used by the same
researcher at different times. Statistical methods exist to
establish quantitative measures of levels of reliability, where
appropriate.
<b>Research competence</b> Researchers engaging in ethical research need to have the
appropriate experience, gualifications and competence to
design and carry out their work, and to do so ethically.
Research ethics committees are often required to consider
whether researchers have sufficient competence as part of
their assessment of research merit (see, for example, the UK
ESRC Framework for Research Ethics, 2015 which enables
grants to be rejected on that basis). Some research
methodologies and disciplines have identified core
competencies, qualifications or certification processes. In other
cases, committees may need to assess claims made to
competence or attempt to discern this from an application. Not
all committees have sufficient competence in the matters that
come before them to make that decision.
<b>Research integrity</b> Definitions of integrity vary across countries, institutions and
disciplines. The choice can reflect whether emphasis is placed
on detection and punishment or on education and culture. The
dominant position in many jurisdictions dwells on misconduct;
where the definition has legal status (as in the United States)
and is meant to hold researchers and institutions accountable,
the acts and degree of intention associated with misconduct
may be tightly demarcated. Where definitions are intended to
promote broader values, the field may be conceived broadly.
ALLEA's European Code of Conduct for Research Integrity refer
to reliability, honesty, respect and accountability. The authors
of the influential Singapore Statement on Research Integrity
argued for fundamental principles relating to honesty,
accountability, professional courtesy and fairness, and good
stewardship of research, as well as 14 professional
responsibilities that together ought to transcend legitimate
national and disciplinary differences.
<b>Research misconduct</b> The United States Federal Policy on Research Misconduct
defined research misconduct tightly in terms of fabrication,
falsification and plagiarism. The threefold definition of

	misconduct has become part of research integrity codes across the world. However, codes and statements developed outside the United States have extended their definition of research misconduct to <i>questionable research practices</i> .
Respect	In this context, respect means having proper regard for the feelings, wishes or rights of another person, group or institution. It is the acknowledgement of <i>Dignity</i> and incorporated in the notion of <i>Due Process</i> . Respect does not commit a researcher or research user to shaping their work precisely in accord with the feelings, wishes or rights of another party: several parties may be involved with different feelings, wishes or rights. It does, however, oblige researchers or research users to take equally serious account of each party and to have clear reasons for departing from their expressions of feelings, wishes or rights.
Responsibility	Responsibility is the condition or fact of being answerable or accountable for something within one's power, control, or management. In this context, it is often taken to mean that researchers should anticipate and assesses the potential implications of their work for both science and society as a whole. While they may not be able wholly to control what is done with their work, they should be able to demonstrate that they have considered its potential consequences. Responsibility is also linked to <i>Accountability</i> and the idea that researchers should to act in a way that shows their understanding of the importance of respecting a wider social interest.
Risk	Risk is the likelihood that research will result in damage, injury, liability, loss, or any other negative occurrence to some group or individual. The risk may fall on the wider society, on some specific section of the society, on an individual taking part in the research, or on the researcher.
Safety	Safety is the effort to mitigate or manage <i>Risk</i> , wherever it may arise. It involves measures to protect the health, well-being and rights of researchers, research participants, particular communities and the wider society. The interests of these groups may be in conflict. There will often be a trade-off between risk and safety: being averse to risk may mean that important knowledge is not acquired while being averse to safety may result in harm to one or more parties to the research. Some aspects of safety may be the subject of legal or regulatory obligations on those who employ researchers, regardless of the choices or preferences of individual researchers.
Sanctions	The word 'sanction' has two meanings in English. It may denote approval or permission to undertake an action. In this context, however, it is used in the legal sense of a penalty intended to create incentives to comply with a law, rule, regulation or instruction. To be effective, sanctions should normally be clearly defined in advance, relevant and proportionate to the offence committed and only administered as a result of <i>Due</i> <i>Process</i> .
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Security	Security is freedom from, or protection against, potential harm (or other unwanted coercive change) from external forces. Its beneficiaries may be individuals and social groups, institutions, or whole societies. Security mostly refers to protection from hostile forces, but it has a wide range of other senses: for example, as the absence of harm (e.g. freedom from want); as the presence of an essential good (e.g. food security); as resilience against potential damage or harm (e.g. secure foundations); as secrecy (e.g. a secure telephone line); as containment (e.g. a secure room or cell); and as a state of mind (e.g. emotional security). The term may also be used to refer to acts and systems intended to provide security, as in the case of 'data security'. Research may jeopardize security in the first sense but may also be expected to deliver security in the second.
Self-plagiarism	Self-plagiarism occurs when authors 'reuse their own previously disseminated content and pass it off as a "new" product without letting the reader know that this material has appeared previously' (Roig, 2013). Self-plagiarism may involve republishing a paper without acknowledgement, dividing one study into several redundant publications, or recycling previously written text without appropriate citation. Self- plagiarism can pose problems for meta-analyses as one study may exercise disproportionate influence if it is counted multiply (particularly if authors disguise the self-plagiarism); it may also infringe publishers' copyright. In some disciplines, material (for example code in information technology, images in visual design) may be reused or repurposed without being understood as breach of integrity (See also <i>Duplicate and</i> <i>redundant publication: Plagiarism</i> ).
Sexism	Actions based on the belief or unexamined assumption that people recognized as members of one sex or gender are less intelligent, able, skilful, etc. than people recognized as members of the other sex or gender. It most commonly refers to actions that assume women's capacities and abilities are inferior to those of men. It may also be extended to cover the

	assumptions made about those individuals who identify
	themselves as 'non-binary', declining to be recognized as
	members of any specific sex or gender.
Sexual harassment	'where any form of unwanted verbal, non-verbal or physical
	conduct of a sexual nature occurs, with the purpose or effect of
	violating the dignity of a person, in particular when creating an
	intimidating, hostile, degrading, humiliating or offensive
	environment' (Directive 2006/54/EC of the European
	Parliament). High profile concerns about abuse of power by
	powerful men in various organisations have also been raised in
	research institutions.
Standards	Statements about the quality of performance that should be
	expected from some activity. These statements may prescribe
	the technical details of the activity and the process required for
	the outcome to be recognized as acceptable. Although
	standards need not have an explicit legal force, they often
	acquire a moral force, such that individuals and organizations
	are expected to comply with them in order to be treated as
	legitimate for relevant social and economic purposes.
Stigmatisation	The process of marking social disapproval of some individual,
	group or institution that is not considered to comply with the
	expectations of those around it. Commonly, this disapproval is
	not based on objective evidence of the deviant aspects of the
	target's behaviour, actions or personal characteristics but may
	still have considerable impact on their social and economic
	opportunities. It is a relevant concern for researchers that
	their work should not unnecessarily compound the
	stigmatization of those individuals or groups who participate.
Transparency	A lack of hidden agendas and conditions associated with some
	action, accompanied by the open availability of all the
	information required for collaboration, cooperation, and
	collective decision making. Agreements, dealings, practices,
	and transactions are open to all for verification. The implication
	of transparency is that every action should be scrupulous
	enough to bear public scrutiny. This includes clarity about the
	rules and reasons behind regulatory measures. In practice,
	transparency may need to be balanced against Confidentiality
	and Stigmatization to protect research participants and their
	legitimate privacy and commercial interests.
Value	In ethical thinking, value goes beyond the economic
	calculations that are often used to produce a single metric in
	order to evaluate the likely costs and benefits of actions for
	individuals and organizations, whether as the one acting or
	being acted upon. The principle of human <i>Dignity</i> implies that
	all human beings and social institutions have an intrinsic value

	and potential to make contributions that are as much spiritual, moral or intellectual as they might be material. This implies that they cannot be treated simply as means to some research goal but are entitled to a degree of respect as a matter of right.
Vested interests	Applies both to individuals and to public and private groups and organisations. Individuals may seek to promote a theory or misrepresent a finding for personal advancement. Can also apply to organisations seeking to control scientific findings for private advantage. Corporate, NGO and government interests associated with matters such as deregulation of banking, private prisons, fracking, fossil fuels have been accused of deliberate distortion of the scientific record at the expense of the public good by overtly or covertly funding pro-industry research, suppressing contrary findings, and falsely discrediting opponents. Similar allegations have been made against political groups who misuse research to favour a particular public policy agenda or ideology.
Vice	Immoral or wicked – but not necessarily unlawful – individual behaviour. It is generally thought to be the result of a weakness of character that applies regardless of context. Vices may be contained by <i>Sanctions</i> but can only be corrected by acts of personal will, which may encouraged by programmes of education, reform or rehabilitation.
Virtue	Morally good or desirable individual behaviour thought to reflect positive strength of character that may be displayed in any context. It may be encouraged through education and reward, although it is not motivated by a desire for personal gain, in either a financial or a spiritual sense.
Voluntarism	The foundational assumption that individuals are free to choose their own goals, and how to achieve them, albeit within certain societal and cultural constraints. These choices are a matter of will rather than being coerced or predetermined. This assumption supposes that, in the absence of contradictory evidence, all human beings have the potential cognitive capacity to make free choices. Provided that they have full information, these choices will accurately reflect their preferences and goals in life – at least as far as they can be realised within that context.
Vulnerability	A limited capacity to protect one's own interests or <i>Security</i> from harm, exploitation or other wrongdoing. It is not a fixed property of individuals or institutions but depends upon the context and resources, material or cognitive, that are available to support the person, group or organization. It may be thought of as an impaired ability to meet the assumptions of <i>Voluntarism</i> .

Whistleblowing	The exposure of information or actions within an organization,
	public or private, that may be considered illegal, unethical, or
	abusive. Where an organization lacks Transparency,
	whistleblowing may be an important means of revealing
	misconduct. As such, it often receives special legal protection
	against potential reprisals. Sometimes incentives may be
	offered to encourage whistleblowing. Researchers who
	uncover misconduct may face difficult choices in deciding
	whether to respect the assurances of confidentiality that are
	usually given to organizations that take part in research or to
	acknowledge a public interest in disclosure.

# **MISCONDUCT**

All systems of social control require choices about the balance to be struck between encouraging or incentivizing good behaviour and sanctioning bad behaviour. The control systems in science are no different. In general, encouraging good behaviour is to be preferred. This generally tends to be more effective. In this particular instance, it also reflects the particular problems of controlling innovation, where the innovator necessarily knows more than the regulator. A virtue-based approach to ethics and integrity seeks to stimulate self-reflection and self-restraint such as to minimize the need for regulatory interventions. Where successful, the innovator anticipates and addresses challenges in advance so that problems are avoided.

It would, though, be naïve to suppose that virtue alone would be sufficient to overcome the competing incentives offered by the reward systems in science, for individuals and organizations, to be less than scrupulous in the conduct of research and the treatment of human subjects. The control system must, then, also have an element of deterrence and sanctioning. While this exists for the protection of wider social interests in preserving confidence in the reported outcomes of research, and in respect for human life and dignity, it will only command confidence if it also meets accepted standards of natural justice for those accused of misconduct.

In the design and development of a fair and acceptable control system, it is likely that the following issues will need to be dealt with:

• Are the definitions of misconduct clear and well-communicated in advance so that miscreants cannot claim ignorance? Equally, does the system avoid punishing scientists for actions that were not considered to be misconduct at the time they were committed? Can the system learn from such actions without sanctioning those who carried them out?

• Is investigation adequately resourced and carried out in a professional, forensic and impartial fashion by independent agents with appropriate expertise under the presumption of innocence?

• Can investigations be triggered by a wide range of social actors who can freely express their concerns and allegations to the investigative body? Can investigations be conducted in a way that respects the professional and career impact of an accusation of wrongdoing on the alleged offender?

• Where the investigative body finds there is a prima facie case to answer, is this evidence considered by an independent tribunal applying appropriate tests and standards of proof with the benefit of both topic-specific expertise and general forensic skills? In particular, is the alleged miscreant fully informed of the case against them and given full opportunity to confront and question witnesses, with appropriate professional support or representation?

• Does the tribunal have available an appropriate and proportionate range of sanctions, including options for shaming and rehabilitation as well as straightforward punishment?

• Is there a process by which tribunal decisions, on both guilt and sanctions, are able to be reviewed at a higher level?

• Are decisions made publicly available and used to inform discussions about the contexts within which misconduct occurs and the incentives and pressures that may have given rise to it?

# ROUTES

# **ROUTES INTO THE PRO-RES FRAMEWORK**

There are separate means for interrogating the Framework according to your sphere of interest. Select your 'role' from the list below. Your roles may, of course, overlap – but so too will some elements of the routes you follow. It may be hard to see all these roles as distinct and, even within role, there may be marked differences about how these roles are performed. Thus, for example, research managers will not all be confronted by the same interests, challenges and concerns. Managers in think tanks, independent research agencies, and in governments departments will sometimes have similar and at other times divergent concerns to deal with. We suggest you choose one role first – follow it through first of all to seek the necessary information and then return for any other route. We only suggest links to sources we have investigated and found to be useful and reliable and seem to us to be largely in agreement with our fundamental values, principles and standards.

Click below if you wish to enter as a:

- Researcher [LINK TO 'FOR RESEARCHERS']
- research manager
- research funders
- research commissioners
- scientific research policymaker
- regulator of research
- reviewer of research
- science journalist
- member of the public
- member of a special interest group
- student

# SAMPLE STEPS "FOR RESEARCHERS"

- LOCATING AN ETHICS CODE OR GUIDELINES APT FOR TOPIC AND METHOD [LINK TO 'A']
- ➢ WRITING AN ETHICALLY SOUND RESEARCH PROPOSAL
- > PREPARING FOR A REC REVIEW
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION
- DATA MANAGEMENT
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

LINKS for other roles:

# **"FOR RESEARCH MANAGERS"**

- LOCATING ETHICS CODES OR GUIDELINES [LINK TO 'A']
- MONITORING A RESEARCH PROPOSAL FOR ETHICS AND INTEGRITY
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- LOCATING AN APPROPRIATE REC
- ESTABLISHING A REC [e.g. discovering apt SOPs]
- DATA MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as researchers]
- CASE STUDIES USEFUL IN SEEING HOW ISSUES HAVE BEEN RESOLVED [LINK TO C]

### **"FOR RESEARCH FUNDERS"**

- LOCATING AN ETHICS CODE OR GUIDELINES APT FOR TOPIC AND METHOD [LINK TO 'A']
- ➢ WRITING AN ETHICALLY SOUND RESEARCH CALL
- ➢ INDICATING NECESSARY REC REVIEW
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- DATA COLLECTION SECURITY
- DATA MANAGEMENT SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

### **"FOR RESEARCH COMMISSIONERS"**

- LOCATING AN ETHICS CODE OR GUIDELINES APT FOR TOPIC AND METHOD [LINK TO 'A']
- ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- BEST PRACTICE IN REC REVIEW
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN ANTICIPATING AND RESOLVING ISSUES [LINK TO C]

## **"FOR RESEARCH REGULATORS"**

- LOCATING APPROPRIATE ETHICS CODES OR GUIDELINES [LINK TO 'A']
- ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- BEST PRACTICES IN REC REVIEW
- THE ROLES OF RESEARCH ETHICS/INTEGRITY ADVISORS [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN UNDERSTANDING ISSUES [LINK TO C]

# **"FOR RESEARCH REVIEWERS"**

- AVAILABLE ETHICS CODES OR GUIDELINES [LINK TO 'A']
- > ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- > PREPARING FOR A REC REVIEW
- RESEARCH ETHICS/INTEGRITY ADVISOR ROLES [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > POINTS TO NOTE FOR DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

# **'FOR SCIENCE JOURNALISTS"**

- > THE RANGE OF ETHICS CODES AND GUIDELINES [LINK TO 'A']
- > THE ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- ➢ THE NATURE OF REC REVIEW
- RESEARCH ETHICS/INTEGRITY ADVISORS AND ADVISORY SYSTEMS [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- ILLUSTRATIVE CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

# **"FOR MEMBERS OF THE PUBLIC"**

- WHAT ETHICS CODES OR GUIDELINES APPLY TO RESEARCH? [LINK TO 'A']
- > WHAT DOES AN ETHICALLY SOUND RESEARCH PROPOSAL LOOK LIKE?
- ➢ HOW IS REC REVIEW CONDUCTED?
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ► HOW DO REC SYSTEMS VARY WITHIN & BETWEEN COUNTRIES?
- WHAT ARE THE REGULATIONS ON DATA COLLECTION, DATA MANAGEMENT AND DATA SECURITY?
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN UDERSTANDING THE KINDS OF ISSUES THAT CAN ARISE [LINK TO C]

# "FOR MEMBERS OF SPECIAL INTEREST GROUPS"

- LOCATING AN ETHICS CODE OR GUIDELINES SUITED TO YOUR INTEREST [LINK TO 'A']
- ➢ HOW CAN RESEARCH PROPOSALS BE MADE ETHICALLY SOUND IN TERMS OF YOUR INTERESTS?
- ▶ WHAT SEPCIAL ELEMENTS OF A REC REVIEW NEED CONSIDERATION FOR YOUR INTERESTS?
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ HOW DO REC SYSTEMS VARY?
- ➢ WHAT ASPECTS OF DATA COLLECTION, DATA MANAGEMENT AND DATA SECURITY NEED TO ACCOUNT FOR YOUR INTERESTS?
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN UNDERSTANDING THE ISSUES INCOLVED IN CONDUCTING ETHICAL RESEARCH [LINK TO C]

# **"FOR POLICYMAKERS"**

- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- WHICH ETHICS CODES OR GUIDELINES ARE AVAILABLE FOR NON-MEDICAL SCIENCES [LINK TO 'A']
- RECOMMENDED WAYS OF MONITORING A RESEARCH PROPOSAL FOR ETHICS AND INTEGRITY
- ➢ WHAT RECS ARE AVAILABLE?
- > JUDGING THE QUALITY OF A REC [e.g. discovering apt SOPs]
- > DATA MANAGEMENT AND DATA SECURITY REGULATIONS
- HEALTH AND SAFETY IN RESEARCH [will lead to same information as researchers and managers]
- THE VALUE OF CASE STUDIES TO ANTICIPATE THE ISSUES THAT CAN ARISE [LINK TO C]

SAMPLE STEP: [A]

# ETHICS CODES OR GUIDELINES

**TEXT:** There are so many codes and guidelines that it can be difficult to locate one that is 'fit for YOUR purpose'. We try here to guide you towards appropriate set of guidelines that might be linked to the topic of the research you are interested in or the methods linked to that research. There is a distinction between 'codes' and 'guidelines' but, for convenience, we refer to them all here as 'guides'.

# INSERT MAPPING CODES AND GUIDELINES of D1.1 – GIVE INSTRUCTIONS ABOUT HOW IT CAN BE INTERROGATED.

DIRECT LINKS TO PROJECTS THAT HELP WITH SPECIFIC INTERESTS:

### **GUIDES to FAIR RESEARCH:**

#### The TRUST Project

The goal of the TRUST Project is to catalyse a global collaborative effort to improve adherence to high ethical standards around the world, to avoid 'ethics dumping' from wealthy to less-wealthy societies, and to advocate fair research practices internationally. It incorporates the SAN code of ethics which offers a model for fair research practices with indigenous peoples. There is also a 'Global Code of Conduct' to encourage fair research and a toolkit for 'Fair Research Commissioning'

http://trust-project.eu/

### **GUIDES to ETHNOGRAPHIC OR ANTHROPOLOGICAL RESEARCH:**

The **European Commission, DG Research and Innovation** commissioned the following report: <u>http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-ethnog-anthrop\_en.pdf</u>

**The American Anthropological Association** offers a website with useful guides to good/responsible 'professional practice' together with a regular blog on some of the contentious issues facing this kind of research:

http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=1942&navItemNumber=65
2

Video/podcasts each for undergraduates, graduates/junior professionals, and IRB members:

http://dperlman.wixsite.com/bioethics2point0/research-ethics-in-anthropology

ADD THE FOLLOWING:

GUIDES TO RESPONSIBLE RESEARCH AND INNOVATION (RRI):

**GUIDES to RESEARCH USING BIG DATA:** 

**GUIDES to COMPUTER-BASED RESEARCH:** 

### **GUIDES TO INTERNET/SOCIAL MEDIA RESEARCH:**

AND...?

# SAMPLE STEP: [B]

# LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR

You might find it helpful to locate professional advice from those who have worked in this field for many years and are capable of assisting in projects from design to dissemination. Some *pro bono* advice might be available, but for anything more than just a simple question, advisors would expect a fee for services. Most advisors can work remotely but face-to-face meetings may also be required at times. Advisors can have different roles in different jurisdictions, varying from advice on researcher conduct, to advice on how research misconduct processes work. You need to be clear what sort of advisor you need and you need to assess their competence on the basis of their career history, references and recommendations.

#### USEFUL GUIDANCE ON RESEARCH ADVISORS:

#### Roles and Functions of Ethics Advisors/Ethics Advisory Boards in EC-funded Projects

While this document is targeted at EC-funded projects specifically, the advice contained can be useful applied whatever the funding source.

http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-advisors\_en.pdf

#### **PRO BONO:**

UK Social Research Association (SRA) Ethics Consultancy Forum for Members only:

http://the-sra.org.uk/research-ethics/ethics-consultancy-forum/

UK Research Integrity Office: http://ukrio.org/get-advice-from-ukrio/

#### FEES REQUIRED: [Short para to be added explaining each of these 'services'.]

Australasian Human Research Ethics Consultancy Services Pty Ltd (AHRECS): <u>https://ahrecs.com/</u>

Helen Kara: <u>https://helenkara.com/</u>

Robert Dingwall: <u>http://www.dingwallenterprises.co.uk/</u>

John Oates (Open University, UK)

Ron Iphofen: <u>https://roniphofen.com/</u>

Helen Busby (<u>helen\_busby@hotmail.co.uk;</u> <u>Helen.Busby@protonmail.com</u>

(Independent research ethics advisor/Consultant to WHO)

....list of other advisors

SAMPLE STEP: [C]

# CASE STUDIES

TEXT: Case studies are a useful way of illustrating problems of ethics and integrity in research in terms of the specific contexts in which the problems arose. The generic values, principles and standards we outlined at the start have to be 'interpreted' by researchers when in the field, in the laboratory or in the archives. The context within which ethical decisions have to be taken can vary considerably. This means that the same principles may be interpreted to take different actions depending on the researchers' understandings of how they should be applied in a specific setting

# ANTHROPOLOGICAL CASES:

Illustrative examples from the American Anthropological Association:

http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=12912&RDtoken=38123&a mp&navItemNumber=731;userID=5089

### SOCIAL RESEARCH CASES:

The **UK Social Research Association**'s Ethics Consultancy Forum has dealt with a range of requests for advice and opinions about how best to act in certain situations. They offer a series of case examples – real world answers to questions raised by researchers.

http://the-sra.org.uk/research-ethics/ethics-consultancy-forum/ethics-cases/

### PUBLICATION/DISSEMINATION CASES:

COPE – the **Committee on Publication Ethics** offers numerous examples of problems of ethics and integrity associated with scientific publication processes:

https://publicationethics.org/cases

### PRO-RES ONSITE CASE STUDIES: (+ explanation of how they might be used)

Each of the following case studies were devised in concert with the Consortium partners and made available as 'standalone' illustrations of problems of ethics and integrity in very specific instances or to be employed in training sessions on research ethics.

# CASE STUDY 1: SALTER'S 'DUCK' AND THE UK WAVE POWER PROJECT

Research into a new and unorthodox energy technology that could displace traditional energy supply methods requires funding. The project receives funding via the administrative structure of the traditional and 'competing' technical system. Funding is constantly delayed and then results of the research assessed by 'experts' who work within the old technology.

**QUESTION:** What are your first thoughts about any ethical implications of conducting and funding such research?

# **POSSIBLE RESPONSES:**

- What are the immediate consequences of funding new technologies that could undermine previous ways of producing energy?
- What 'interests' are involved?
- What 'larger' policies influence the research and the views of funders and government?
- Given such consequences does it matter who funds the research?
- Is there room for misconduct depending on how are funds disbursed?
- Similarly does it matter who analyses the results?

### FEEDBACK OF DETAIL:

The new technology was Wave Power energy (specifically Salter's Duck). The 'old' technology was nuclear power via the Atomic Energy Authority.

### FURTHER RESPONSES:

• Any further issues raised in light of further information?

### Background and Context

Research into marine wave power began in the UK in the early 1970s when Professor Stephen Salter of Edinburgh University began experiments using a dynamically shaped float that linked via a spine to a series of others which bobbed up and down in the waves. The Duck is a 300-tonne floating canister designed to drive a generator from the motion of bobbing up and down on waves like a duck. It is still regarded as the most efficient of any wave power system produced, converting up to 80% of the wave energy to electricity which was to be then cabled ashore. All the experiments were successful until 1982 when the work suddenly stopped.

The problem arose from the control of all renewable energy research during the 1970s and 1980s coming from an organisation that was part of the United Kingdom Atomic Energy Authority. The Department of Energy's research and development advisory council (ACORD) committee operated at long range from all the projects and was recruited largely from the nuclear and the depletable energy industries. In other words, wave power research was funded and controlled by the regulators of the nuclear, coal and gas industries.

By 1982, a consultant was able to report that the duck could be expected, with further development, to produce electricity at a cost of around 5.5 pence per kilowatt-hour, a price competitive with nuclear power (the most expensive commercial generation process in use in Britain). Clive Grove-Palmer, a respected department engineer seconded to work on the duck project, estimated that the cost could be got down around 3 pence per kilowatt-hour. ACORD met in 1982, excluding Grove-Palmer, and accepted a secret report, prepared by a unit based at British Atomic Energy Authority headquarters, claiming that wind power had more immediate commercial possibilities than wave power, and research funds should be shifted to it. The department, which was packed with nuclear supporters, had instructed ACORD to reduce its renewables research budget from £14 million to £11 million. At the time, the Department was spending around £200 million on nuclear research.

It was eight months before wave power researchers were allowed to see the report on which ACORD based its decision to junk their work. Then, in January 1983, a research unit based at the Atomic Energy Authority came out with another report concealing the good figures for the Duck by averaging them in with figures for all wave power projects. This gave a non-commercial figure of 8-12 pence per kilowatthour. Apparently still not satisfied that they had killed the Duck, opponents of the project then produced figures overestimating capital costs by a factor of 10, massively underestimating the reliability of undersea cables, and claiming that in mass production each Duck would cost about the same as one prototype.

Grove-Palmer took early retirement as a result of the decision. "I resigned ... because they asked me to write the obituary of wave power. There was no way I could do that ... We were just ready to do the final year of development and then go to sea."

After a long campaign to save the project, Professor Salter's team was forced to disperse in early 1987. "We must not waste another 15 years and dissipate the high motivation of another generation of young engineers", wrote Salter in a memorandum to the House of Lords committee on renewable energy. "We must stop using grossly different assessment methods in a rat race between technologies at widely differing stages of their development. We must find a way of reporting accurate results to decision makers and have decision makers with enough technical knowledge to spot data massage if it occurs. I believe that this will be possible only if the control of renewable energy projects is completely removed from nuclear influences."

*QUESTION: Are there any obvious errors of judgment – challenging principles of ethics and integrity in how this research was developed and managed?* 

### **POSSIBLE RESPONSES:**

- Are there clear conflicts of interest involved here? What might they be?
- Could the degree of funding be considered realistic? (Is that an issue of ethics and/or integrity?)
- Is 'relative funding' of any consequence?
- How could the figures have been allowed to be deliberately misleading?
- Was there adequate peer review of the process?

III The View from the Researchers

Prof. Salter gave the following assessment of reasons for the failure of the Project to a House of Commons Parliamentary Select Committee in 2001:

"If I had to supply reasons for the failure of the first UK wave programme I would cite over-optimism, the attempt to make very big (2GW) power stations and to assess infant devices too quickly. The programme was properly supported and enthusiastically led from 1976 to 1983, a period of only seven years, and then entered a very unhappy phase where researchers felt that they were always on the defensive. An account of this has been given to a Committee of another place (HL paper 88, 21 June 1988 page 178 and 190-206) and it does not, at present, seem helpful to repeat it here."

Salter went on to answer the Committee's question:

# What role should wave and tidal stream energy have in the Government's renewable energy strategy? Should they have a higher priority?

"This must depend on whether the Government and its civil servants really want renewable energy to succeed or whether they want to appear to be supporting a programme but really want it to fail. Over the years many of the officials with whom we dealt certainly seemed to want success but this often proved to be a dangerous career move. I must warn the Committee that this danger is not confined to officials. There was a Commons Energy Committee which looked into renewables in 1992. A copy of my evidence (pages 62 to 68 of volume III) is attached. One of the Committee's recommendations was the resurrection of the wave energy programme. The Energy Committee was immediately disbanded!

Always there seems to be a layer, or indeed layers, of senior people with negative views about renewables and the power to make them stick. This power seems to be inversely related to technical knowledge of the subject or technology in general. If the concerns about carbon levels, global warming and long-term supplies of fossil fuels are well founded, then the Government policy should be that every possible renewable source should be thoroughly researched to the point that it could rapidly be employed at some stage in the future. The demonstration of this capability would do much to limit the dangers of a manipulated market for oil or gas and could be regarded as part of a nation's defences. The costs of a vigorous research programme are very small compared with the total spending on fuel or the possible future consequences of having insufficient energy supplies. The spin-off in unexpected directions has, so far, been quite sufficient to justify what has been spent. Diversity between renewable sources with different availability reduces the problems caused by lack of firmness of supply. This could be further reduced by the use of renewable sources for the manufacture of hydrogen, methanol, ammonia or even potable water."

Question: There appears to have been (still is?) a group of people in senior levels with the power to impose their own agenda? What issues does that raise?

# **POSSIBLE RESPONSES:**

- Can and should political responsibilities be kept separate from those of the scientists/researchers?
- Should those officials (elected and/or appointed) be in a position to override the scientific findings?
- Is the problem one of honesty and transparency?

• Is there any way in which both the scant funding and the deliberate sabotage could be justified?

# IV Lessons learned: How should national funding for new technologies be managed?

Prof. Salter's further responses to HoC Committee's questions offer lessons:

"...Private investors must protect their investment by secrecy in a way that is totally foreign to academics, even if a large fraction of the money is coming from public sources. There are even stronger motives for secrecy following poor productivity or the loss of a prototype. Mistakes will then be repeated by others. It does not have to be like this. Following an aircraft accident there is a very expensive investigation with the most detailed information supplied to and carefully studied by the entire industry. This should be an obligation in return for receipt of public money."

Strict central/ministerial direction would violate the independence of research funding councils. "…This independence is important because there is also documentary evidence that an official from the Energy Technology Support Unit (ETSU) at Harwell (then part of the United Kingdom Atomic Energy Authority) tried hard... to discourage support for wave energy from Brussels. Over-strict co-ordination stifles original ideas. I am, therefore, on balance in favour of open published consultation between independent bodies and a degree of anarchy."

However, this general view has been suddenly challenged by a serious co-ordination problem concerning test tank facilities which I would like to draw to the attention of your Committee. It concerns test facilities for wave energy research, which I regard as essential and which are expensive enough to have to be nationally co-ordinated."

"Funding for most academic work, now including waves, is the responsibility of the Engineering and Physical Sciences Research Council, which is given money by Government but notionally makes independent decisions. I have some evidence that this independence was not complete when, in 1986, a proposal for work on wave energy was rejected on the grounds that it was not strategic, as defined by the Renewable Energy Advisory Group set up by the DTI."

Question: How can an effective balance be struck between central government funding, private investment and research councils?

# **POSSIBLE RESPONSES:**

- Government control of private enterprise should be limited. (Why?)
- Government control of research council funding should be limited. (Why?)
- Governments have the right/duty to direct 'strategic research and funding'. (Why?)
- Should peer review be entirely separated from funding and strategic issues?
- Is full transparency realistic?
- What ethical issues arise from striking the balance for new technology research between 'national coordination' and 'anarchy'?

# SUMMARY LESSONS LEARNED: GUIDANCE FOR POLICYMAKERS

This case offers an example of trying to do research with integrity while the researchers were placed in a 'no win' situation. This is a 'real world' example and considerable ethical reflection is required to fully understand the 'context' in which the research had to be conducted. The lessons are apt for new technologies that are framed by political, economic and ideological constraints – together with the evident research misconduct that took place and can only be described as 'sabotage'. Again such actions must be understood in terms of the balance of many interests, most of which are not linked to the 'profession' of research.

Policymakers and regulators have a responsibility to consider how best to manage emergent technologies in light of strategic contradictions. What may be seen as 'anarchy' from one perspective, may be legitimately viewed as 'healthy competition' from another. For example, in the later 1990s there was a distinct drive towards the globally co-ordinated regulation of genetics research – the 'risks' estimated to be so high that such uniform standards were seen as a necessary alternative to a dangerous anarchy. Little consideration was given to the possibility of allowing diverse national regulation leading to a 'regulatory competition' which could then be studied to assess what sort of regime worked best rather than having global standards imposed by unaccountable bioethicists.

Thus Salter's Duck illustrates the problem of balancing independence in research, free markets in technological developments and governmental dirigeism. Centralised coordination can stultify genuine innovation if researchers are prevented from pursuing their own promising lines of thought. The possibility of 'dead ends" and the 'waste' of scarce funding resources might have to be risked for exciting and productive innovation to win through.

The major ethical lesson arising out of these observations is that though transparency in governmental actions may seem the most moral course, that may be balanced against strategic requirements that ensure societal safety and stability. How to identify such a rationale against 'political expediency' remains moot.

# CASE STUDY References

Physics and Ethics Education Project: <u>http://www.peep.ac.uk/content/1113.0.html</u>



https://www.greenleft.org.au/node/3401 Green Left Weekly Issue 64

Houses of Parliament Select Committee on Science and Technology Minutes of Evidence Retrieved 10 July 2018 https://publications.parliament.uk/pa/cm200001/cmselect/cmsctech/291/1031401.htm

PRO-RES (788352)

# CASE STUDY 2: TINDER AND TRAVEL

Researchers Jenna Condie and Garth Lean decided to research the ways in which location-aware smartphone apps mediate contemporary travel experiences. They focused on Tinder, an app designed to help people meet potentially like-minded others who are nearby. Tinder has a premium version which allows users to change their geolocation and so 'meet' people in a place they're due to visit before they arrive.

Social media research has been around for a few years now but generally involves the largest platforms such as Twitter and Facebook. Research via Tinder is a recent development. Tinder is a location-aware smartphone app with tens of millions of users worldwide (Twitter and Facebook have hundreds of millions of users). Tinder enables its users to view, and either accept or reject, the profiles of other users who are physically near to them. Users can reject others by 'swiping left' and accept by 'swiping right'. If two people accept each other, a match is made and they can then communicate by private message. Thus far the service is free, but there is also a premium 'Passport' feature which lets users change their geolocations and so 'travel' digitally. This means users can make connections and plans with people in a place they're due to visit before they arrive.

Jenna Condie and Garth Lean, researchers based in Sydney, became interested in the possibilities of using Tinder to research ways in which location-aware smartphone apps mediate contemporary travel experiences (Condie, Lean, and Wilcockson 2017). On moving to Sydney, Jenna had begun using Tinder to help her meet people locally, which led to her considering its potential as a data source. She discussed this with her colleague Garth, a researcher of mobilities and travel. He was not a user of Tinder and was initially reluctant to get involved because the app has a reputation for enabling casual sex. Also, when they started discussing the possibilities of their research with other colleagues, some perceived it as trivial and unsuitable for serious academic research. These conflicting perceptions contributed to difficult identity issues which led to some methodological decisions that the researchers later overturned.

STIMULUS: What are your first thoughts about any ethical implications of conducting such research?

# POSSIBLE RESPONSES MAY ADDRESS:

- What is the 'value' added or potential for knowledge gain? (Is it 'worth' doing?)
- To what extent will researchers' own and others' perceptions of social media affect how social media research is approached and conceived?
- What ethical protocols might apply or are available for this sort of work?
- Given the work is necessarily innovative, to what extent do standard guidelines, codes etc. help researchers?
- Under what circumstances should researchers fully disclose their research purpose when entering a social media site where they plan to collect data?
- How fully could the available research ethics review system understand the ethical implications of this research?

• To what extent can research be considered ethical if researchers change their methodology part way through?

# Engaging the site

Both Condie and Lean were explicit in their Tinder profiles that they were using the app for research purposes. Lean, less familiar with location-aware social discovery apps, also joined some others: Bumble, Happn, and Backpackr. Both researchers found difficulty in managing the boundary between their personal and professional identities in these online spaces. For example, Lean received a message from an unknown woman via Bumble which said 'I am so ready to be used for academic purposes', and Condie received one from a man on Tinder saying 'Am I now a case study?' They found that their online and offline lives could not be kept as separate as they might have wished.

# STIMULUS: What are the implications of this?

### POSSIBLE RESPONSES MAY ADDRESS:

- Such research raises the boundaries between...
- ...the personal and the professional,
- ...the virtual and the real,
- ...the public and the private,
- ... in research using location-aware social media -
- ... or any social media research for that matter.
- To what extent can/should each of these issues be kept separate from online research activity?
- For any that can or should, how might this be achieved?
- To what extent should this also be a consideration in conventional research?

### **Ethical Concerns**

These and other interactions raised ethical issues long before Condie and Lean had applied for formal ethical approval. They struggled to find precedent for ethical research on Tinder, though the Association of Internet Researchers' ethical guidance helped by suggesting that research design in online spaces should be context-specific.

Some aspects of Tinder are in itself ethically questionable. For example, Tinder takes a binary approach to gender and sexual orientation. Users have to declare their gender as male or female, and state whether they wish to see profiles of women or men. This excludes non-binary people, plus others who define as genderqueer or genderfluid, and it makes no space for trans people or bisexuals. This means that collaboration is necessary for research on Tinder if data from both women and men are to be included. **STIMULUS:** It appears the researchers effectively started their research before seeking ethical approval. Is that acceptable or 'normal'? Given the 'ethically questionable' nature of Tinder should they even be studying it?

POSSIBLE RESPONSES MAY ADDRESS:

- How can researchers most usefully and ethically plan research in a new field of study where there is little or no literature to guide them?
- What aspects of research work are ethically acceptable to carry out before formal ethical approval is received?
- When and how can researchers justify studying people taking part in ethically questionable activities?
- What are the implications of conducting research in an online arena that is in itself ethically questionable?

# Seeking Formal Ethics Approval

The researchers initially decided on a design involving an extractive quantitative content analysis of Tinder user profiles, to establish the prevalence of "Tinder travel" as a social phenomenon, followed by an online questionnaire. Their original plan was to conduct the content analysis manually, analysing profiles according to a predetermined coding scheme. This would not require a record of users' profiles. One reason they chose this approach is that there is no way to ask for informed consent on Tinder except from people with whom you are a 'match'. The researchers argued that the information in users' profiles was pre-generated and already in the public domain.

However, as reasonably experienced social media researchers, they were also aware that this doesn't necessarily mean it is fair game for researchers. Also, Tinder profiles cannot be viewed unless they meet the viewer's specified criteria for attributes such as gender, age range, and location, and they are not searchable in the way that profiles are on other platforms such as Twitter and Facebook. This raises questions of exactly how 'public' are Tinder profiles anyway? The researchers also cite surveys by NatCen (2014) and Ipsos MORI (2015) showing that when people are asked, they are more likely to refuse than consent to their online data being used by researchers. These findings add weight to the argument that data people generate online is not necessarily regarded as public, even if a member of the public can view it under some circumstances. This shifting boundary between the public and the private is a recurring problem for social media researchers.

Condie and Lean then discovered an automated way to collect data using an Application Programming Interface (API). Tinder's Terms of Service (ToS) clearly state that no user should use any automated method of data mining. However, the researchers argued that the ToS as a whole was focused on preventing commercial use of the app or any detriment to users. Their view was that their purposes were academic, not commercial, and that no harm could come to users because of the data management procedures they had developed.

Condie and Lean gained formal ethical approval to use this method.

### STIMULUS:

• How should researchers work with social media companies' terms and conditions?

• What are your views of the REC's actions in approving the study?

# POSSIBLE RESPONSES MAY ADDRESS:

- When is it acceptable to use automated data mining techniques for research and when should researchers mine data manually?
- What effect have recent research ethics scandals, such as those involving Cambridge Analytica and Facebook, had on social media research?
- How should researchers manage conflicts between ToCs and ethical research practice?

# Amending the Research Design and Protocol

The researchers received formal ethical approval to use the API but then thought better of it. This was partly because of the tenuousness of their argument about the ToS and partly because the API would create a dataset which would lead to a permanent record of users' profiles outside of Tinder.

At a more macro level, this kind of 'big data' approach ignores issues of privilege and social inequality. Condie and Lean cite Mason (2016) who showed how Tinder users' images of themselves doing humanitarian and unpaid work, intended to attract others, reproduce hierarchies of race.

They also cite Race (2015) who points out that Tinder users are sufficiently privileged to have access to a smartphone and the Internet, as well as private spaces for sexual encounters. The ability to travel is a further sign of privilege and Condie and Lean found they were unable to ignore the replication of existing social structures in the interactions made possible through Tinder. In particular, Tinder's API is called 'The Hoes'. This misogynistic label is in line with the widespread abuse of women in society, including online spaces. The researchers wanted no complicity with such abuse. Instead, they moved into using more participatory, critical and feminist methodologies to enable them to pay closer attention to the relationship between Tinder and the problematic social structures that create and/or perpetuate inequalities.

Condie and Lean suggest a few reasons for their initial gravitation towards a quantitative approach. These include: the prominence of 'big data' in academic and other research; the attraction of the way data mining puts distance between researcher and participants which reduces the troubles of identity management in online spaces; the way the ethical framework for their institution privileges positivist methodologies. This can restrict the possibility of beginning a research project within an alternative ethical framework.

# STIMULUS:

- Recognising that research designs may need to be fluid given circumstances in the field what should the researchers do about the fact they have received REC approval?
- To what extent should researchers be concerned with replications of privilege and/or inequality?

### POSSIBLE RESPONSES MAY ADDRESS:

- When should researchers go back to RECs for further input?
- How much influence should RECs expect to have over unforeseen changes during the research process?
- If researchers should be concerned with replications of privilege and/or inequality, should they be concerned with all such replications or some more than others?
- If 'some more than others', which, and why?

# V – Outcomes and Reflections for Future Practice

Condie and Lean did go ahead with the online questionnaire. However, despite widespread promotion of the project on various social media platforms and online travel forums, they only received a couple of dozen responses. These were useful and led to some follow-up interviews. The data from these, together with the researchers' reflections on their ethical experiences and their revised methodologies, led them to move towards a digital storytelling method for the next phase of their research. However, this again threw up new ethical problems, particularly around the anonymity of participants and others who participants spoke of within their stories. Condie and Lean had to devise a moderation system for the website where the stories were published, so that they could change names or locations to avoid any danger of individual identification.

The researchers claimed in their ethics application that no relationships would exist between participants and researchers. However, they found that this was not achievable in practice, because they had to use their personal Facebook profiles to log into Tinder. That connected the two social networks and this, plus the use of geolocations, meant that people they knew were likely to be included in their sample.

It is clear that the relationship between this research and ethical governance was troubled throughout. Condie and Lean worked within a prescribed structure of ethical governance which they had learned to game. They reflect on the need for researchers doing innovative work to lobby for the system to be changed to enable alternative approaches. They conclude that when you can hold your research field in your hand, and take it with you everywhere you go, then the rules of research need to be rewritten (Condie, Lean and James 2018); a call that was being made simultaneously by researchers on the other side of the planet (Samuel et al 2018).

### STIMULUS:

• Did this work fail or did it succeed?

# POSSIBLE RESPONSES MAY ADDRESS:

- The researchers claimed that no relationships between researchers and participants/responders was likely. Was this naïve, or duplicitous and misleading to the REC?Are new 'rules' for research required as a result of innovative work?
- What value is there (if any) in accounts of such messy research?

### SUMMARY LESSONS LEARNED: HOW RESEARCH RESULTS ARE USED

Research results such as these, with much of their 'mess' on show, are rarely published. It is notable that this account was found in a book chapter, not an academic journal. Yet these kinds of results are really useful for reflection and learning about ethical issues in social media – and other – research. To assess the usefulness of research results, the practical experiences of trying to do research ethically and with integrity are necessary. In other words, this cannot be done in abstract reflection, but rather in terms of 'real world' research examples. Indeed, much ethical reflection requires the experience of the 'context' in which research has to be conducted. So what are the summary 'lessons' learned here?

Research governance and ethics review systems must keep pace with methodological and technological innovation. This requires a flexibility not often afforded by ethics codes or guidelines that are too fixed in their use. A 'dynamic' capacity has to be built in to such structures so that they adequately and rapidly change with the times. Internet research in general and social media research in particular invites such responsiveness. But such rapid change is also seen in biotechnologies, nanotechnologies, AI/robotics, environmental sciences, labour markets, economic and financial spheres and so on.

Policymakers and regulators have an equal responsibility to consider whether and how rules and redress can be developed to facilitate such responsiveness. Some recognition that existing systems and structures may have to be tested and challenged by researchers coming across the restrictions, injustices, perpetuations of inequality and so on that can be perpetrated by the rigidity of existing regulation. It is only by conducting innovative practices can the flaws and limitations of existing systems for governance and ethics review be disclosed. Ethics reviewers are party to this, requiring a culture of facilitation, openness to new approaches and tolerance of the practical difficulties of research in the field.

But regulators cannot be left to produce ethical practice alone – all stakeholders are involved. Research conducted with integrity depends upon: "...distributed collective responsibility. Ethical research practice becomes a mutual accomplishment of all participants – research subjects, researchers, commissioners, funders and managers." (Iphofen 2009: 166) Research results from a case such as this Tinder example show that all stakeholders have an obligation to learn from each other and ensure the lessons learned are carried forward into different topics, fields, disciplines and professions.

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### STILL TO COME:

CASE STUDY 3: 'IN PROCESS' - Place hacking ethnography

# Some examples of ADDITIONAL RESOURCES TO BE LINKED TO 'ROUTES':

### Better practice templates and advised links:

Annotated Bibliography (See 'References' below) Free, valid, informed consent procedures Research ethics review procedures Data protection and management (Links to GDPR and National DPA legislation) Health and safety Publication/research dissemination (COPE – GLOBAL AND FLOWCHARTS) Education and training Monitoring in the field Indemnity 'RI' in narrow sense!

TREAD and its completed approved ethics application forms

etc...?

# 5) SHORTENED VERSION OF THE FRAMEWORK: 'WEB-READY'!

# FRAMEWORK DRAFT [FINAL CONCISE WEB-READY VERSION]

DRAFTING THE FRAMEWORK – some sample pages offering route suggestions for the website.

# FRONT PAGE

(See 'Background' if you are interested - LINK) – RECOMMENDED LINKS ARE HIGHLIGHTED

### The PRO-RES Guidance Framework for Non-Medical Sciences

# PRO-RES is a European Commission-funded project aiming to PROmote ethics and integrity in nonmedical RESearch. PRO-RES is "FOR" research!

**GOAL:** is to devise and build a supported *guidance framework* for all non-medical sciences and humanities disciplines adopting social science methodologies. The Framework will be ethical, comprehensive, and offer practical help to researchers. The Framework will be constructed in consultation with the full range of stakeholders in responsible research and innovation.

The Guidance Framework will be found on this platform and will guide people through the issues and concepts to resources on good practices in research. These will include codes, guidelines, archived documents and other sources.

**PRO-RES aims to:** remove confusion and offer a user-friendly resource. Our target audience includes all those interested in promoting and securing research that is ethically sound and displays scientific integrity.

THE FRAMEWORK is... under construction... so we need your help to make sure it achieves the intended aims.

FOR MORE ABOUT THE PROJECT BACKGROUND – GO TO (LINK TO 'BACKGROUND')

TO ENTER THE FRAMEWORK – GO TO (LINK TO FRAMEWORK PORTAL)

SEND YOUR SUGGESTIONS FOR IMPROVEMENT TO: .....

# (Background)

#### **BACKGROUND TO THE PRO-RES PROJECT**

**MAIN GOAL:** PRO-RES aimed to use the full range of stakeholders, to devise and build a supported *guidance framework* for all non-medical sciences and humanities disciplines adopting social science methodologies. The framework is intended to meet the highest standards of research ethics and scientific integrity and to be comprehensive, covering the full range of issues and concerns. It will be of practical help in guiding interested parties to ways of achieving reliable and trustworthy research. The targeted stakeholders include researchers, reviewers, regulators, research managers and policymakers and, not least, a representative range of research participants.

**WHY IS SUCH A PROJECT NECESSARY?** Trying to behave ethically and with integrity when conducting research can prove to be complicated given the wide range of codes, guidelines and frameworks. Regulations are diverse and inconsistent, and review practices vary considerably – between countries, institutions, disciplines and professions. As multinational and interdisciplinary research grow, it is vital that the confusion arising from disparate approaches should be minimised.

**THE FOCUS:** Decision takers and policymakers should be seeking evidence to support their work from the range of expertise on offer. Any errors, fraud or corrupt practices by researchers can damage the environment and the social, economic and cultural structure of society. But sound, reliable, transparent research, not driven by or subservient to ideology or undeclared vested interests, produces robust evidence that can benefit people and planet. It is in the interests of both the scientific community and policymakers to ensure the evidence produced is reliable and trustworthy and ethically generated.

### THE CHALLENGE:

Being a 'good' scientist in both the moral and methodological sense is not easy. All researchers have to compromise, make choices and balance potential conflicts and contradictions. Conducting research requires a balance between many political, institutional and professional contradictions and constraints. How should a scientist balance professional responsibilities with obligations to whoever funded their research? How can the safety of both researchers and participants be assured in, for example, conflict areas? How is the ethic of benefit sharing with participants to be addressed? When should privately commissioned research be shared in the public interest? When should intellectual property be kept private – or owned and sold? Robust evidence helps to defend expertise against blind ideology. Vested interests, or those that conflict with the values of scientific integrity, must be challenged by virtuous researchers acting with integrity. The PRO-RES Guidance Framework aims to help them do just that.

# FRAMEWORK PORTAL

**BEFORE GOING ON... IT IS IMPORTANT TO UNDERSTAND...** 

### The underlying assumptions of the PRO-RES Framework:

Below are the common elements to be found in existing codes, guidelines and frameworks. These can be regarded as the basic assumptions of the PRO-RES framework:

VALUES and VIRTUES: Throughout most of the existing codes and guidelines there appears a commonly held understanding that the virtuous researcher/scientist holds to certain values. These include honesty, supportive collaboration, and respect for participants. They should demonstrate qualities of care, kindness and compassion and take responsibility for all their actions. That includes a responsibility to think through what the consequences of their work might be for society, communities, groups and individuals. The freedom to conduct scientific research must be matched by enabling potential participants the freedom not to be obliged to take part. Nonetheless, at times research can require considerable courage on the part of all participants, and this too is considered a virtue of responsible scientific practice. These values and virtues need to be supported by the cultures and structures of the institutions in which researchers work.

**VICES:** These include incompetence, indolence, malicious deceit, the misrepresentation of facts and findings, fraudulent use of data, plagiarism and other forms of corrupt practices – such as harassment, bullying and/or nepotism. Stigmatising or prejudicial language, distortions, or data-gathering biases such as racism/ethnocentrism and sexism are reproved. So too are practices intended to entrench social exclusion or marginalise specific social categories – such as those with a disability or the aged or infirm or ethnic groups. The failure to credit or acknowledge the value of all contributions to a research activity is also a vice.

**PRINCIPLES:** In order to bear responsibility scientists must participate in open and democratic processes and be accountable for their actions. They need to operate in a collaborative and collegial manner, apply their data collection, findings and research outcomes proportionately, justly and fairly. The larger community – both public and professional – should benefit from and not be harmed by research activities. The involvement of participants should be voluntary, though specific principles are needed to cover public and covert observations of behaviour or phenomena that could not be studied in any other way when necessary for societal benefit. Both researchers and researched need to be accorded a degree of autonomy– both in terms of how research is conducted and whether they continue to participate. Reliable research will depend upon a just and equitable selection and treatment of participants.

**STANDARDS:** Standards to ensure that research is conducted ethically and with integrity are contained with sets of rules for good governance. These will include standard operating procedures for the evaluation of project proposals and the system of ethics oversight – the form and content of research ethics review committees or any other review, monitoring or ethics approval process. Equally important are the regulated means for safeguarding scientists, their subjects, their findings and their intellectual property. Sanctions must be available for those researchers that fail to fulfil their obligations without good reason. Results must be auditable and provision made for honest and constructive critique of malpractice – such as whistleblowing. Standards for due process must include means for resolving conflicts of interest.

TERMS AND CONCEPTS WE ARE USING: 'LINK TO GLOSSARY OF TERMS'

WHAT WE MEAN BY RESEARCH MISCONDUCT: LINK TO 'MISCONDUCT'.

WE ADVISE THAT YOU RETURN TO CHECK ON THESE TERMS AS YOU INTERROGATE THE FRAMEWORK.

NOW ENTER THE FRAMEWORK BY CHOOSING YOUR ROUTE: (LINK TO 'ROUTES')...

# **MISCONDUCT**

All systems of social control require a balance between encouraging good behaviour and sanctioning bad behaviour. The control systems in science are no different. In general, encouraging good behaviour is preferable, because it is usually more effective. In this instance, it also reflects the problems of controlling innovation, where the innovator necessarily knows more than the regulator. A virtue-based approach to ethics and integrity seeks to stimulate self-reflection and self-restraint to minimize the need for regulatory interventions. Where successful, the innovator anticipates and addresses challenges in advance so that problems are avoided.

It would, though, be naïve to suppose that virtue alone could overcome the competing incentives offered by the reward systems in science, for individuals and organizations, to be less than scrupulous in the conduct of research and the treatment of people. The control system must, then, also include sanctions. While this protects wider social interests by preserving confidence in the reported outcomes of research, it will only be effective if it also meets accepted standards of justice for those accused of misconduct.

In the design and development of a fair and acceptable control system, it is likely that the following issues will need to be dealt with:

• Are the definitions of misconduct clear and well-communicated in advance so that miscreants cannot claim ignorance? Equally, does the system avoid punishing scientists for actions that were not considered to be misconduct when they were committed?

• Is investigation adequately resourced and carried out in a professional, forensic and impartial fashion by independent agents with appropriate expertise under the presumption of innocence?

• Can investigations be triggered by a wide range of people who can freely express their concerns and allegations to the investigative body? Can investigations be conducted in a way that respects the professional and career impact of an accusation on the alleged offender?

• Where the investigative body finds there is a prima facie case to answer, is this evidence considered by an independent tribunal applying appropriate tests and standards of proof with the benefit of both topic-specific expertise and general forensic skills? In particular, is the alleged offender fully informed of the case against them and given full opportunity to confront and question witnesses, with appropriate professional support or representation?

• Does the tribunal have available an appropriate and proportionate range of sanctions, including options for shaming and rehabilitation as well as straightforward punishment?

• Is there a process by which tribunal decisions, on both guilt and sanctions, are able to be reviewed at a higher level?

• Are decisions made publicly available and used to inform discussions about the contexts within which misconduct occurs and the incentives and pressures that may have given rise to it?

# **ROUTES**

# ROUTES INTO THE PRO-RES FRAMEWORK

There are separate means for interrogating the Framework according to your sphere of interest. Select your 'role' from the list below. This will lead you to sources we have investigated and found to be useful, reliable, and largely in agreement with our fundamental values, principles and standards.

Click below if you wish to enter as a:

- Researcher [LINK TO 'FOR RESEARCHERS']
- research manager
- research funders
- research commissioners
- scientific research policymaker
- regulator of research
- reviewer of research
- science journalist
- member of the public
- member of a special interest group
- student

# SAMPLE STEPS "FOR RESEARCHERS"

- LOCATING AN ETHICS CODE OR GUIDELINES APT FOR TOPIC AND METHOD [LINK TO 'A']
- WRITING AN ETHICALLY SOUND RESEARCH PROPOSAL
- > PREPARING FOR A REC REVIEW
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION
- DATA MANAGEMENT
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

LINKS for other roles:

# **"FOR RESEARCH MANAGERS"**

- LOCATING ETHICS CODES OR GUIDELINES [LINK TO 'A']
- MONITORING A RESEARCH PROPOSAL FOR ETHICS AND INTEGRITY
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ LOCATING AN APPROPRIATE REC
- ESTABLISHING A REC [e.g. discovering apt SOPs]
- DATA MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as researchers]
- CASE STUDIES USEFUL IN SEEING HOW ISSUES HAVE BEEN RESOLVED [LINK TO C]

### **"FOR RESEARCH FUNDERS"**

- LOCATING AN ETHICS CODE OR GUIDELINES APT FOR TOPIC AND METHOD [LINK TO 'A']
- > WRITING AN ETHICALLY SOUND RESEARCH CALL
- ➢ INDICATING NECESSARY REC REVIEW
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- DATA COLLECTION SECURITY
- DATA MANAGEMENT SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

### **"FOR RESEARCH COMMISSIONERS"**

- LOCATING AN ETHICS CODE OR GUIDELINES APT FOR TOPIC AND METHOD [LINK TO 'A']
- ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- BEST PRACTICE IN REC REVIEW
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN ANTICIPATING AND RESOLVING ISSUES [LINK TO C]

# "FOR RESEARCH REGULATORS"

- LOCATING APPROPRIATE ETHICS CODES OR GUIDELINES [LINK TO 'A']
- ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- BEST PRACTICES IN REC REVIEW
- THE ROLES OF RESEARCH ETHICS/INTEGRITY ADVISORS [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN UNDERSTANDING ISSUES [LINK TO C]

# **"FOR RESEARCH REVIEWERS"**

- AVAILABLE ETHICS CODES OR GUIDELINES [LINK TO 'A']
- > ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- > PREPARING FOR A REC REVIEW
- RESEARCH ETHICS/INTEGRITY ADVISOR ROLES [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > POINTS TO NOTE FOR DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

# **'FOR SCIENCE JOURNALISTS"**

- > THE RANGE OF ETHICS CODES AND GUIDELINES [LINK TO 'A']
- > THE ELEMENTS OF AN ETHICALLY SOUND RESEARCH PROPOSAL
- ➢ THE NATURE OF REC REVIEW
- RESEARCH ETHICS/INTEGRITY ADVISORS AND ADVISORY SYSTEMS [LINK TO 'B']
- ➢ VARIATIONS IN REC SYSTEMS
- > DATA COLLECTION, MANAGEMENT AND SECURITY
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- ILLUSTRATIVE CASE EXAMPLES HELPFUL IN RESOLVING ISSUES [LINK TO C]

# **"FOR MEMBERS OF THE PUBLIC"**

- WHAT ETHICS CODES OR GUIDELINES APPLY TO RESEARCH? [LINK TO 'A']
- > WHAT DOES AN ETHICALLY SOUND RESEARCH PROPOSAL LOOK LIKE?
- ➢ HOW IS REC REVIEW CONDUCTED?
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ► HOW DO REC SYSTEMS VARY WITHIN & BETWEEN COUNTRIES?
- WHAT ARE THE REGULATIONS ON DATA COLLECTION, DATA MANAGEMENT AND DATA SECURITY?
- > HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]

CASE EXAMPLES HELPFUL IN UDERSTANDING THE KINDS OF ISSUES THAT CAN ARISE [LINK TO C]

# "FOR MEMBERS OF SPECIAL INTEREST GROUPS"

- LOCATING AN ETHICS CODE OR GUIDELINES SUITED TO YOUR INTEREST [LINK TO 'A']
- HOW CAN RESEARCH PROPOSALS BE MADE ETHICALLY SOUND IN TERMS OF YOUR INTERESTS?
- ▶ WHAT SEPCIAL ELEMENTS OF A REC REVIEW NEED CONSIDERATION FOR YOUR INTERESTS?
- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- ➢ HOW DO REC SYSTEMS VARY?
- WHAT ASPECTS OF DATA COLLECTION, DATA MANAGEMENT AND DATA SECURITY NEED TO ACCOUNT FOR YOUR INTERESTS?
- HEALTH AND SAFETY IN RESEARCH [will lead to same information as research managers]
- CASE EXAMPLES HELPFUL IN UNDERSTANDING THE ISSUES INCOLVED IN CONDUCTING ETHICAL RESEARCH [LINK TO C]

# **"FOR POLICYMAKERS"**

- LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR [LINK TO 'B']
- WHICH ETHICS CODES OR GUIDELINES ARE AVAILABLE FOR NON-MEDICAL SCIENCES [LINK TO 'A']
- RECOMMENDED WAYS OF MONITORING A RESEARCH PROPOSAL FOR ETHICS AND INTEGRITY
- ➢ WHAT RECS ARE AVAILABLE?
- > JUDGING THE QUALITY OF A REC [e.g. discovering apt SOPs]
- > DATA MANAGEMENT AND DATA SECURITY REGULATIONS
- HEALTH AND SAFETY IN RESEARCH [will lead to same information as researchers and managers]
- THE VALUE OF CASE STUDIES TO ANTICIPATE THE ISSUES THAT CAN ARISE [LINK TO C]

SAMPLE STEP: [A]

#### ETHICS CODES AND GUIDELINES

**TEXT:** it can be hard to find the right set of codes or guidelines (all of which we call 'guides'). This will help you to find guides that are linked to your research topic or relevant methods.

# INSERT MAPPING CODES AND GUIDELINES of D1.1 – GIVE INSTRUCTIONS ABOUT HOW IT CAN BE INTERROGATED.

DIRECT LINKS TO PROJECTS THAT HELP WITH SPECIFIC INTERESTS:

#### **GUIDES to FAIR RESEARCH:**

#### The TRUST Project

The TRUST Project aims to catalyse a global collaborative effort to improve adherence to high ethical standards, to avoid 'ethics dumping' from wealthy to less-wealthy societies, and to advocate fair research practices internationally. It incorporates the SAN code of ethics which offers a model for fair research practices with indigenous peoples. There is also a Global Code of Conduct to encourage fair research and a toolkit for Fair Research Commissioning.

http://trust-project.eu/

#### **GUIDES to ETHNOGRAPHIC OR ANTHROPOLOGICAL RESEARCH:**

The **European Commission, DG Research and Innovation** commissioned the following report: <u>http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-ethnog-anthrop\_en.pdf</u>

**The American Anthropological Association** offers a website with useful guides to good/responsible professional practice together with a regular blog on some of the contentious issues facing this kind of research:

http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=1942&navItemNumber=65

Video/podcasts each for undergraduates, graduates/junior professionals, and IRB members:

http://dperlman.wixsite.com/bioethics2point0/research-ethics-in-anthropology

### ADD THE FOLLOWING:

**GUIDES TO RESPONSIBLE RESEARCH AND INNOVATION (RRI):** 

**GUIDES to RESEARCH USING BIG DATA:** 

**GUIDES to COMPUTER-BASED RESEARCH:** 

**GUIDES TO INTERNET/SOCIAL MEDIA RESEARCH:** 

AND...?

SAMPLE STEP: [B]

### LOCATING A RESEARCH ETHICS/INTEGRITY ADVISOR

You might find it helpful to locate professional advice from those who have worked in this field for many years and are capable of assisting in projects from design to dissemination. Some *pro bono* advice might be available, but for anything more than just a simple question, advisors would expect a fee for services. Most advisors can work remotely but face-to-face meetings may also be required at times. Advisors can have different roles in different jurisdictions, varying from advice on researcher conduct, to advice on how research misconduct processes work. You need to be clear what sort of advisor you need and you need to assess their competence on the basis of their career history, references and recommendations.

#### USEFUL GUIDANCE ON RESEARCH ADVISORS:

#### Roles and Functions of Ethics Advisors/Ethics Advisory Boards in EC-funded Projects

While this document is targeted at EC-funded projects specifically, the advice contained can be usefully applied whatever the funding source.

http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-advisors\_en.pdf

#### **PRO BONO:**

UK Social Research Association Ethics Consultancy Forum: <u>http://the-sra.org.uk/research-ethics/ethics-</u> consultancy-forum/ (SRA members only)

UK Research Integrity Office: http://ukrio.org/get-advice-from-ukrio/

### FEES REQUIRED: [Short para to be added explaining each of these 'services'.]

Australasian Human Research Ethics Consultancy Services Pty Ltd (AHRECS): https://ahrecs.com/

Helen Kara: <u>https://helenkara.com/</u>

Robert Dingwall: <u>http://www.dingwallenterprises.co.uk/</u>

John Oates (Open University, UK)

Ron Iphofen: <u>https://roniphofen.com/</u>

Helen Busby (helen\_busby@hotmail.co.uk; Helen.Busby@protonmail.com

(Independent research ethics advisor/Consultant to WHO)

....list of other advisors
### SAMPLE STEP: [C]

### CASE STUDIES

TEXT: Case studies are a useful way of illustrating problems of ethics and integrity in research in terms of the specific contexts in which the problems arose. The generic values, principles and standards we outlined at the start have to be interpreted by researchers when in the field, the laboratory or the archives. The context within which ethical decisions have to be taken can vary considerably. This means a principle may lead to different actions depending on the researchers' understandings of how it should be applied in a specific setting.

#### ANTHROPOLOGICAL CASES:

Illustrative examples from the American Anthropological Association:

http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=12912&RDtoken=38123&a mp&navItemNumber=731;userID=5089

#### SOCIAL RESEARCH CASES:

The **UK Social Research Association**'s Ethics Consultancy Forum has dealt with a range of requests for advice and opinions about how best to act in certain situations. They offer a series of case examples – real world answers to questions raised by researchers.

http://the-sra.org.uk/research-ethics/ethics-consultancy-forum/ethics-cases/

#### PUBLICATION/DISSEMINATION CASES:

COPE – the **Committee on Publication Ethics** offers numerous examples of problems of ethics and integrity associated with scientific publication processes:

https://publicationethics.org/cases

### 5) NEXT STEPS

*Designing the Interactive Platform*: Decisions need to be taken about who designs the platform. There is enough 'in-house' (i.e. consortium partners) experience for this to be done without seeking external work.

*Content Management*: An early discussion and decision about the content management strategy is necessary, for both the repository and for the forums, social media etc. The long-term plan needs to cover contingencies so that it's not totally dependent on the presence of one or two specific committed individuals. People come and go, so the plan needs to accommodate the transfer of roles between individuals without the system as a whole grinding to a halt.

# ABBREVIATIONS

AcSS The UK Academy of Social Sciences (Consortium Partner)

WS Workshop

# REFERENCES

THE PREFERENCE IS TO DEVISE AN **ANNOTATED BIBLIOGRAPHY** TO COVER ALL DELIVERABLE DOCUMENTS WHICH WILL EVENTUALLY BE HOUSED IN the FRAMEWORK (IDEALLY WITH DOI'S FOR ALL REFERENCES).

The Annotated Bibliography will be done in a data-friendly way e.g. on a spreadsheet not in a Word document. It will have predetermined drop-down lists for categories and keywords to be assigned to each repository item – a new category/keyword can be assigned, but needs to be added to the category/keyword list and will then appear in the drop-down list to be linked to a repository item. If done properly, this data can be easily converted for use within a website database structure. We will use the bibliography authoring process as the first step in designing the repository's structure.

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