This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement

PRO-RES

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

## Deliverable Title: Case Studies and the Framework: lessons learned

## Deliverable Number: 3.3

**Project ID:** **788352**

**Prepared by:** **Dr Helen Kara**
**Lead Author:** **Helen Kara**
**With Contribution From: EASSH, UTartu, K&I, CUC**

| | |
|---|---|
| *Deliverable Number* | **3.3** |
| *Work Package* | **3** |
| *Deliverable Responsible Partner* | **AcSS** |
| *Contractual delivery date* | |
| *Delivery date* | |
| *Total pages* | **19** |

# VERSION LOG

| Version | Date | Author/reviewer | Change Details |
|---|---|---|---|
| **0.1** | **01/09/2021** | **Ron Iphofen** | **First Draft** |
| **0.2** | **19/10/2021** | **Helen Kara** | **Second Draft** |
| **0.3** | **28/10/21** | **E. Detsis** | **Final Draft** |

# EXECUTIVE SUMMARY

This deliverable summarises and describes the methods and events adopted to assist the evolution of the PRO-RES Framework, and captures the lessons learned. The aim was to test the general applicability of the Framework to the wide-ranging themes and topics envisaged by the original Call and Proposal. Additionally it was recognised that the Framework would have to be effective across the full range of communities of interest/stakeholders, hence it was tested in a range of events including interviews, workshops and training/continuous development meetings (CPD). Opportunities to present at invited events allowed initial introductions of the project and its products, with a focus on the Framework. The Project was introduced during most of the active national case studies forming part of WP5, then comments and opinions from those case studies were incorporated into the Framework. After the mid-term Project conference, the emergent Framework was bench-tested within the Consortium. Partners were asked to consider how the Framework would be received by the research agencies, researchers and 'influencers' that they were familiar with, and in a range of research sites and settings, and whether further modifications could be suggested. Once the Framework had reached a fairly stable form (to be found on the Website) a training/CPD module was designed, again to be flexible enough to be delivered to the range of different possible users and other stakeholders. Different routes through the Tools and Resources that form key elements of the Framework could be adopted according to the interests of the training audience. Several modules have been delivered and more are anticipated even after the end of the Project. The Framework will remain flexible enough for module evaluations to be incorporated as appropriate, to ensure its continuing relevance to a wide range of stakeholders.

There were a range of different forms of 'case studies' which 'tested' the Framework in a variety of ways: some were cpd events (not just conferences and workshops), all the case studies conducted in the national context – (SRA, UKRIO, Croatia, Estonia etc.) were about whether a Framework is of use/will be used or simply engaged with 'if necessary' by the different agencies involved in setting ethics codes/guidelines. Such actions were not envisaged in the original proposal as primary 'research engagements' given this was a CSA (coordinating and support action). Hence the framework testing was conducted in light of opportunities to network/inform relevant parties/agencies of the aims of the framework and its relevance and utility in a variety of different professional, national and international contexts. Impact assessment and further primary research will depend upon further funded projects.

# INTRODUCTION

The draft Framework was developed from discussions at ten 1-2 day workshops held across the EU with a range of stakeholders including science/technology experts, funders/research councils, policymakers, regulators, and representatives of related projects. These stakeholders identified problems, recommended solutions, and suggested ways for the Framework to incorporate these solutions. This is covered in detail in D2.1.

We had intended to test and refine the draft Framework with a series of high-level round tables, working lunches and other meetings, but due to the COVID-19 pandemic we had to use telephone and online

interviews instead. Interviewees included policy makers and advisers, think tanks, civil society representatives, funders, researchers, journalists, academics and other stakeholders. We conducted 49 interviews and one small group discussion to test the Framework, all of which were carefully recorded and analysed. This is covered in detail in D2.3.

We also tested and sought feedback on the Framework at a range of events throughout its development. These will be covered in detail in this report.

## EVENTS

This deliverable suffered from an unexpectedly elongated process due to the unforeseen COVID-19 pandemic which interrupted the planned meeting schedule and sequencing of key events. This delayed the production of a draft PRO-RES Framework that could be tested within the consortium and with outside EGOs.

There was however an opportunity to treat the stakeholder engagements as a means of guiding the development of the Framework, the building and editing of the website and the planning of effective training/CPD events. In effect the natural sequencing of this deliverable was improved by beginning with stakeholders as the anticipated thought experiments – but with 'outsiders' to the Project in the first instance – and delaying such an event with consortium partners until the developed Framework was in a state of readiness to test properly externally as a training/CPD event. Also, the need to move everything online had an unexpected positive element in enabling some people to attend events when they would not have been able to attend in person.

In all 25 opportunities were taken, throughout the development of the Framework, to test it out and seek feedback for use in the Framework's development. Details of these events are in appendix 1. They range from large conferences to small workshops. Some were training/CPD events which also served as in vivo testing of the Framework, with feedback and suggested amendments sought via participant evaluations of the training. Many of the PRO-RES partners regularly deliver training/CPD to universities, government research agencies, and research reviewers, and so were easily able to deliver such training/CPD events, with the number and frequency depending on requests from their networks following appropriate publicity.

We received feedback from over one thousand individuals from a wide range of countries and professions, and made as much use of that feedback as we could during the development phase of the Framework. These events also served to disseminate the Framework widely within the EU and beyond.

## CASE STUDIES

Five in-depth case studies were conducted during the project, to explore research governance and conduct as practised by various organisations and networks. These case studies were selected for the range of research-related activities they cover, from government research, to independently commissioned research, to research seeking evidence to inform policymaking. The case studies focused on:

1. The International Network of Governmental Science Advice (INGSA), looking at how the network considers research ethics and integrity issues

2. A project to provide a common framework for ethics review and ethics support for universities and other research organisations in the UK, sponsored jointly by the United Kingdom Research Integrity Office (UKRIO) and the Association of Research Managers and Administrators (ARMA (UK))
3. The process of updating the 2003 ethical guidelines of the Social Research Association (SRA), whose members are mostly in the UK and Ireland – the updated guidelines were published in 2021
4. The process leading to the signing of the Estonian Code of Conduct for Research Integrity in 2017
5. The Croatian Agency for Personal Data Protection (AZOP), looking at data protection, privacy, and GDPR

One key learning point that emerged from this work was the need for a balance between the ideal and the practical in frameworks for ethics and integrity in research. Another was that delegating responsibility for research ethics and integrity to a specialised team leads to a culture of compliance rather than one of engagement. We learned from the example of GDPR that prescriptive frameworks using incentives and sanctions can help to deepen commitment. However, prescriptive frameworks are only appropriate for some discrete elements of research ethics and integrity. Much ethical work is inextricably linked with the context and the prevailing circumstances, which constantly change and so make prescription impossible.

Analysis of the case studies supported ten recommendations for people creating, adopting, or using ethical codes or guidelines. Full details of the case studies, their analysis, and the recommendations are in D4.6.

## SUMMARY FEEDBACK FROM EVENTS AND CASE STUDIES

Through the events listed in appendix 1, and the case studies detailed in D4.6, the PRO-RES project learned some key lessons. First, the understanding of research ethics and integrity principles, and the application of their practice, varies between countries, professions, disciplines, and institutions. While the variations may not all be large, the overall picture is very variable.

Second, people's views of outputs can differ quite considerably. At times we have heard completely contradictory views of a particular iteration of the Framework, with some people at an event describing it as confusing and over-complicated, while others described it as user-friendly and a very valuable resource. At some events all those attending approved the Framework as it stood, while at others there were suggestions for improvement – sometimes contradicting suggestions made at other events. Perhaps the most crucial learning point from this is that no Framework can ever be constructed which will completely suit everyone. Therefore we have worked in an iterative way to arrive at a version of the Framework which represents as much of others' input as we have been able to include, and we know from feedback at the more recent events that the Framework now pleases most people, most of the time.

There is of course still work to be done, as no Framework can be static while the world continues to change. The Framework needs an effective search facility that yields information from all areas of the website. Also, several respondents asked for more targeted tools for the Toolbox. And the Framework should continue to be used for CPD: there is a module in appendix 2 which should be adjusted carefully to meet the needs of each specific audience. Most audiences will be made up of very busy people who are unlikely to devote too much time to considering ethical issues, particularly if they don't understand the relevance to their own profession or sector. We have learned that it is more effective to offer a targeted webinar for one hour than a more general and/or longer event.

Another unresolved issue is to do with the Accord. Its wording has been thoroughly discussed and consensually agreed. However, it is not clear how to encourage people to sign up to the Accord. At the

PRO-RES final conference, Yves Dumont of the European Commission's Research and Integrity Team suggested that the Accord might become part of EC research funding guidance. This kind of incentive should encourage people to sign up.

The work does not stop here. There are plans for another CPD webinar in Croatia for members of the University of Pula ethics board at the beginning of November. Also, we have received interest in doing some training for the UK Government Social Research Unit in late 2021 or early 2022. No doubt there will be other such events arranged and held by other partners.

# APPENDIX 1

**Appendix 1: Events for testing and seeking feedback on the Framework:**

**Westminster Higher Education Forum**, London (11 October 2018) – attended by John Oates. This forum included around 100 senior people from government, research councils, universities and other research organisations, and academic publishers. The focus was on protecting research integrity and improving ethical governance. Key lessons learned for PRO-RES development: fraud, corrupt or lazy practices by researchers can lead to serious damage to society and the physical environment. Reliable and transparent research, divorced from political ideology and undeclared vested interests, produces robust evidence that benefits social wellbeing and societal progress.

**World Health Organisation Symposium on the Future of Digital Health Systems** (6–8 February 2019), Copenhagen, Denmark – *Building a European Framework for Ethics in Digital Health* – presentation by John Oates to around 30 people from a total of approximately 200 delegates.

The new challenges of ethics and integrity in digital health were discussed and ways new approaches in research ethics could be used to reason about these new challenges were described. It was explained that the simple patient protection model was not adequate to deal with the more complex ethics issues that arise with online data, social media, fitness and health apps and digital health delivery systems.
A key lesson for PRO-RES was that the storage and use of personal data in digital systems with internet connectivity raises complex issues around consent. In particular, the application of AI to personal health data raises the 'black box' issue, where 'fully informed consent' is not possible because even the researchers cannot 'see' inside the 'box', nor can they predict the future uses to which AI outputs can be applied. Concepts of 'dynamic consent' and 'trust' were identified as potential solutions, along with the use of virtue ethics as a reasoning tool.

**UK Research Integrity Office (UKRIO) Conference**, London (8 May 2019) – attended by Robert Dingwall. This conference focused on the research integrity landscape in the UK and beyond, and was attended by almost 200 people. Key lessons learned for PRO-RES development: awareness, understanding and application of research ethics varies between disciplines, professions, sectors and nations.

**EU National Research Ethics Committees (NREC's) annual conference 2019 in Iasi, Romania -** Ron Iphofen was invited to attend by DG R&I and presented elements of PRO-RES (on vulnerability and 'dynamic consenting'.)

**Qualitative Research Workshop/Conference:** AcSS delivered a workshop on 22 November 2019, facilitated by Robert Dingwall and Helen Kara with support from John Oates and Ron Iphofen, and attended by around 30 invited researchers, publishers and funders. The event focused specifically on qualitative research ethics - in sociology, anthropology, psychology, design, computer science, etc. There is a strong legacy of policies being devised from quantitative research models that then cause all sorts of problems for qualitative researchers. How do you assure integrity when it comes to trusting honest reports from a participant observer whose work cannot be replicated because of the passage of time and whose data may not be shareable without breaching other expectations about participant confidentiality? The Open Science movement and data-sharing initiatives have been very dismissive of these concerns but the PRO-RES Framework needs to acknowledge them. Informed consent is another problem in this field, as are proper relationships with the people that one encounters in research sites. There is a danger that we will address a range of relevant topics in workshops where qualitative researchers are a minority voice and end up with something that effectively silences their concerns rather

than joining them all up in a coherent fashion. PRO-RES needs to engage the relevant communities and ensure their concerns are acknowledged in the final Framework.

**PRO-RES mid-term conference in Brussels, 4 February 2020:** around 100 delegates from 18 countries in Europe, Asia, Africa and the Americas. Delegates included think-tank representatives, policy advisers, policy makers, policy analysts, Government researchers, independent researchers, academics, lawyers, journalists, ethics specialists, publishers, social scientists, natural scientists, economists, and others. The Accord was discussed for 90 minutes in five break-out groups. Delegates also gave feedback on the draft Accord during the breaks in the conference, using stickers and Post-It notes. Then there was a round-table discussion among experts leading to key learning points: acting ethically takes resources of time and money; ethics and the law have an uncertain relationship; we need to recognise that there are few certainties in this era of paradigm shifts; the EU is doing a good job of prioritising ethics in science; principles must make sense in the context where they are applied; we need to set, test, and publicise standards, and incentivize people to use them; it is important to educate people through discursive engagement around clear principles; transparency – of funding, sources of evidence, etc – is key. Also, the Accord could be very useful to countries that don't have a national equivalent.

**Changing research culture – Ethics in non-medical research, SOPS4RRI conference**, Rome (19 March 2020) *Influencing policymaking with ethical evidence: the PRO-RES Project*, interactive workshop led by Ron Iphofen

**Paper presented at the World Congress of Bioethics, The World Association of Bioethics**, (June 18 2020*) Promoting Integrity in the Use of Results from Non-Medical Research* – by Dónal O'Mathúna, Ron Iphofen, Emmanouil Detsis.

**Think tanks round table** – EPC event 3 September 2020. Attended by 29 think tank representatives. Fabian Zuleeg wrote a discussion paper on *An Ethical Framework For Think Tanks* arguing for a framework based on the principles set out in the Accord: independence, a multi-stakeholder approach, transparency, and good governance, with core funding being made conditional to think tanks' commitment to these principles. The round table provided an opportunity for representatives to give their views on the discussion paper, which were very positive, and to begin the process of considering how the Framework might be implemented in the sector. The key learning point for PRO-RES was the need to find a universal set of criteria which are inclusive to all sectors including the think tank sector, a diverse sector made up of comparatively small organisations which work very differently from academic institutions. Transparency was seen as the most important principle and representatives recognised that the PRO-RES Framework could already bring valuable solutions even though, at this time, it was still a work in progress. One concern raised was that while this discussion was very useful indeed, it included only the representatives of think tanks that were already in favour of acting in accordance with agreed standards of ethics. Involving those that are uninterested or not in favour would be a challenge. There is detailed information about this event in D3.4.

**PROMOTING HEALTH IN LIGHT OF COVID-19: THE MAIN ETHICS ISSUES** – presentation by Ron Iphofen to consortium for EU-funded SPICES Project – how the PRO-RES Project can help (basis for CPD module). (8 0ctober 2020)

**'In vitro' test of the website with Consortium partners** feedback gathered and amendments made (2 March 2021) The 'in vitro' test of the website was led by Ron Iphofen – format and content was conducted in an online session with Consortium partners on 2nd March 2021. A scripted event (see Appendix) was stepped through as if the partners were external stakeholders. Comments were made and feedback given as the test run was ongoing. The scripted event could be run by any partner as an

introduction to the website, how it works and what it offers. But it was generally agreed that it would not 'count' as a research ethics/integrity training or CPD event as such and another simple course structure should be provided, based on the website content, to achieve that end.

**University of East Anglia, UK: Annual International Qualitative Research Methods Symposium** – Building Trust with Experiences and Experts: What can qualitative methods tell us about building trust? Ron Iphofen 'Constructing Ethical Evidence: Can we rely on the virtues of a reflexive qualitative researcher to generate trust? – the PRO-RES Project' (15 April 2021).

**Round table on AI and misinformation** – EPC event 3 June 21. Attended by 39 people including policy advisers and analysts, academics, scientists, researchers, and other stakeholders. This round table introduced the Framework and discussed the key challenges that researchers identify regarding accessing data and monitoring it for bias and misinformation. It discussed how more transparency in AI could give way to data and monitoring for bias and misinformation and thus contribute to more transparency and ethical policy advice and policies. The key learning point for PRO-RES was that AI must be governed by ethical standards such as the Framework, not led by industry.

**Publishers workshop**: 15/07/21 – Ron Iphofen led this CPD based on the pilot with Emerald Global publishers (UK, EU and US) – good evaluation of the 'training' together with suggestions for other publishers and the role of publishers in general.

**Online meeting with Senior Researcher(s), UK Home Office** (05/08/21) – Ron Iphofen led an introduction to PRO-RES resources to support aim to strengthen and refresh their in-house ethics advisory group: specific resources relevant included – advisors, RECs systems, SOPs, principles/values/standards, mission statement/constitution, ethical evidence and policymaking.

**Journalists' round table** – EPC event 6 July 21. Attended by 37 people. Introduced the Framework and discussed the critical need for decision-makers dealing with the COVID-19 crisis to be informed with evidence-based and ethically conducted policy advice from experts and researchers. Recognised the link between public trust and evidence-based policy making. Covered the important role of journalists in translating research for policymakers and generating policies. The key learning point for PRO-RES was that policy evidence should inform policy-making, otherwise there are serious cultural and structural damages.

**Sixty-minute briefing on public trust and evidence-based policymaking: lessons from the COVID-19 response** – 7 July 21. Attended by 56 people. Introduced the Framework and discussed the impact of the pandemic on public trust. The key learning point for PRO-RES was the critical need for decision-makers dealing with the COVID-19 crisis to be informed with evidence-based and ethically conducted policy advice from experts and researchers.

**Health practitioners/researchers workshop**: 28/07/21 – CPD webinar Ohio State University. The Framework was presented by Ron Iphofen. All responses to the Framework were positive and no improvements were suggested.

**Cross-SWAFS Stakeholder Forum for Responsible Open Science: Inaugural Meeting** – 30 September 2021. This was attended by representatives of 16 other SWAFS projects. Ron Iphofen represented PRO-RES and gave a short presentation of the project and the framework. This was not a test of the Framework, it was a dissemination activity. However, it did serve to raise awareness.

On 5 October 2021 Zvonimir Koporc held two CPD webinars in Croatia, one for the CUC Ethics Board (social science) attended by four professors and two post-docs, and one for the UNI-RI Department of Biotechnology Ethics Board (lab science and IT) attended by four professors. Everyone was happy with

the quality of the information in the Framework, though the social scientists were more certain of the Framework's overall value than the biotechnologists.

On 6 October 2021 the Centre for Ethics of the University of Tartu in Estonia hosted a testing event introduced by Margit Sutrop and Kristi Lõuk. Seven people attended from five institutions including funding agency representatives, policy influencers, academic research managers, and research practitioners. The Framework was presented and feedback gathered. The response to the Framework was favourable, with the materials and resources being regarded as good and useful. Those present questioned whether/how the Framework could help to foster common understanding and harmonisation of existing codes and guidelines, and help to foster critical thinking. Key learning point: there is room for improvement in the search function.

On 13 October 2021 Zvonimir Koporc held a meeting for around 25 people, presenting results from the PRO-RES project to CUC administration rector and vice-rectors, CUC ethics board, AZOP representatives and representatives from the Croatian Agency for Mobility and EU Funds. The numbers at this meeting were unfortunately limited due to the COVID-19 measures. The main focus was on data protection and those attending gave a very favourable response to the Framework.

Also on 13 October 2021 Alfonso Alfonsi, Maresa Berliri and Giovanna Declich hosted an event to present the Framework to Italian stakeholders. They had nine participants from academia, research, policy analysis, city administration, IT and housing. The participants expressed their interest in the Framework and highlighted the usefulness of its dissemination and endorsement at European as well as National level. The ethics of non-medical research is at present a highly topical issue in Italy and is being addressed by research bodies and Universities (e.g. La Sapienza University in Rome has recently set up its Ethics Committee for Non-Medical Research - CERT), hence the need for guidance and support instruments. Each country has different regulations and approaches to research ethics. In the context of international projects, it would be very useful to have a European agency for research ethics. Usefulness of the PRO-RES Framework for its reflexive approach to virtue ethics so that the researchers or research users are involved in an ongoing conversation on why research is being done, what it is for, and how to anticipate possible impacts and risks (in line with Responsible Research and Innovation).

# APPENDIX 2: STANDARD CPD – PRO-RES FOR ALL STAKEHOLDERS

**SLIDE 1**

Thank you for giving me/us the opportunity to introduce you to the European Union-funded PRO-RES Project. What I hope to do is to let you see the benefits of the work we have been doing for those working in your field, but also for the full range of stakeholders and, hopefully, society in general.

**SLIDE 2**

The plan for this short session/webinar is to explain what PRO-RES is about, and how it could benefit your work, run through some elements of the website and then allow plenty of time for discussion and questions. I hope to answer any questions you might have but I am also looking for suggestions for how we might improve on what we have done so far.

**SLIDE 3**

Put simply the primary aim of PRO-RES is to "PROmote ethics and integrity in all non-medical RESearch – from ideas to outcomes."

To accomplish this PRO-RES is producing a Guidance Framework which:

- encourages policymakers and their advisors to seek evidence for their decisions from research that has been conducted ethically and with integrity;
- covers the wide spectrum of non-medical research; and
- offers practical solutions for all stakeholders, that will comply with the highest standards of research ethics and integrity.

* = 'everything else', includes health and biological – not medical/clinical.

**SLIDE 4**

This work is about the evidence 'supply chain'. All too often policies are built on ideology rather than good evidence, on vested interests and subjective perceptions rather than fair, transparent and robust research findings. So we wish to support the production of 'ethical evidence' – and encourage decision takers to seek out such evidence rather than cherry pick only information that suits a particular political agenda.

To address these issues – along the supply chain – we need to convince all stakeholders to act with integrity at every stage: from the initial research 'idea' or problem to be confronted, through the data gathering and analysis, to the dissemination and sharing of findings, to their application in policies that are also rigorously tested and evaluated.

**SLIDE 5**

When we talk of 'stakeholders' we mean the full range: researchers, funders, reviewers, regulators, research managers, policymakers & their advisors and the disseminators – publishers, journalists, bloggers, media organisations and, not least, society in general – the people being researched and for whom the policies are ostensibly being developed.

NB WE INCLUDE RESEARCH PRACTITIONERS….

This is no easy task since the interests of these different stakeholder 'communities' are not necessarily always congruent – but one thing they should hold in common is the adoption of ethical practices in their evidence-gathering and sharing. Errors, fraud or corrupt practices can damage society, as well as impacting the physical environment. But sound, reliable, transparent research, not subservient to 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 policy makers use the best evidence. That is how to generate trust in their actions and the effectiveness of their policies.

**SLIDE 6**

We have deliberately kept as much of the Guidance Framework as possible on the Project website.


You will see that this is deliberately not a complex presentation – simple images and clear labelling is important to this being user-friendly.

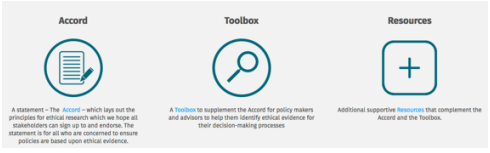
Our tag line reflects that simplicity – that **good research should lead to better policies**.

If you scroll down you see the classical Graeco-Roman building which represents the three columns on which the PRO-RES Framework is built: The Accord statement, a Toolbox and Resources.

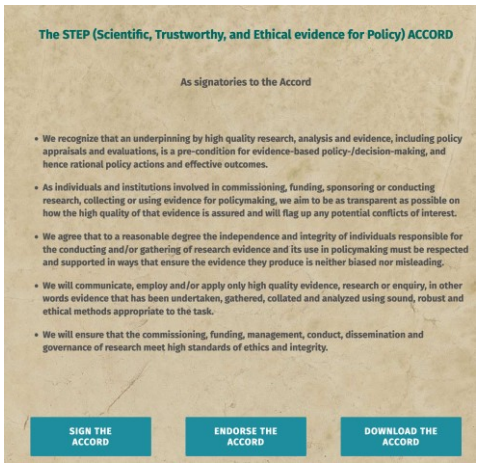

(Continue to scroll down)

There is an explanation and a link to each of these elements as you scroll down.

Hover and open the drop-downs/ups.



Scroll down to ACCORD:




The ACCORD is designed as a straightforward code-like statement that can be compared to codes in the medical field such as the Oviedo Convention and the Helsinki Declaration. In that sense it is a statement that all stakeholders doing and using 'good' research and scientific practice should be able to sign up to. This has been drawn up in such a way that all evidence gatherers and all evidence-users should see it as consistent with their principles, their standards and their values. Indeed it would be hard to imagine who could not sign up to these aims and still claim to be producing and applying 'good' evidence.

Obviously what we mean by 'good' – is research and scientific practice that is conducted ethically with integrity and is also methodologically sound and reliable.

You need to read through this statement and, if you do agree, we would love you to sign up to it. For some umbrella organisations and professional associations, it is hard for them to formally sign up to since they can't be considered as 'representative' of their constituent members. But organisations like that could endorse or recommend the Accord.

**A lot of work went into producing this statement to make sure we didn't miss anyone out. It was particularly important that the wording of the Accord was acceptable to reputable think-tanks as well as to research performing organisations.**

If you want to know more about what went into this and what each of the statements actually mean then you can scroll down step through 'The Principles and Rationale Behind the Accord'.


This explains in detail the assumptions behind each statement. It's better to go through that at your leisure. [Open out and explain.]

What matters more is the next step – to put the ACCORD principles into operation we have made available a 'Toolbox'. The 'tools' in this box are a series of direct questions that anyone could ask about research evidence.

We felt it important that this was not too complicated a set of questions – in fact there is a lot of common sense behind them in that these are just the kinds of tests you should apply to evidence to ensure that it has been gathered ethically.

*The key ethical questions to be asked about any research output, scientific finding, evidence-based policy advice or similar are:*

*WHO did WHAT to WHOM, WHEN, WHERE, HOW and WHY?*

*AND how were the findings PUBLISHED, DISSEMINATED &/or APPLIED?*

*AND what were the CONSEQUENCES of the use to which the findings were put? (EVALUATION)*

The questions are framed in the past tense – so they can be about work that has already been completed. But it is just as easy to change them into the future tense and use them as the basis for writing an ethical research proposal. (in fact we have conducted some ad hoc research ethics reviews for independent researchers just to test that out.)

There are several routes to the Toolbox….

… but when you get there these are the crucial questions to be asked of any evidence gathering or research that has been done.

**The following questions are addressed in the toolbox:**

WHO did the research/conducted the enquiry/provided analysis or advice?

HOW did they do the research or what did they base their advice and analysis on?

WHOM/WHAT was being studied?

WHY was the research/analysis conducted?

WHEN/WHERE was the research/analysis conducted?

Was the research REVIEWED in advance for quality considerations?

What were the OUTCOMES of the research/analysis?

You can click on each of these questions to see how they can be pursued in more detail.

For example, click on:

WHO did the research/conducted the enquiry/provided analysis or advice?

This takes you to:

## WHO were the researchers and the research agency?

**For the individual researcher:**

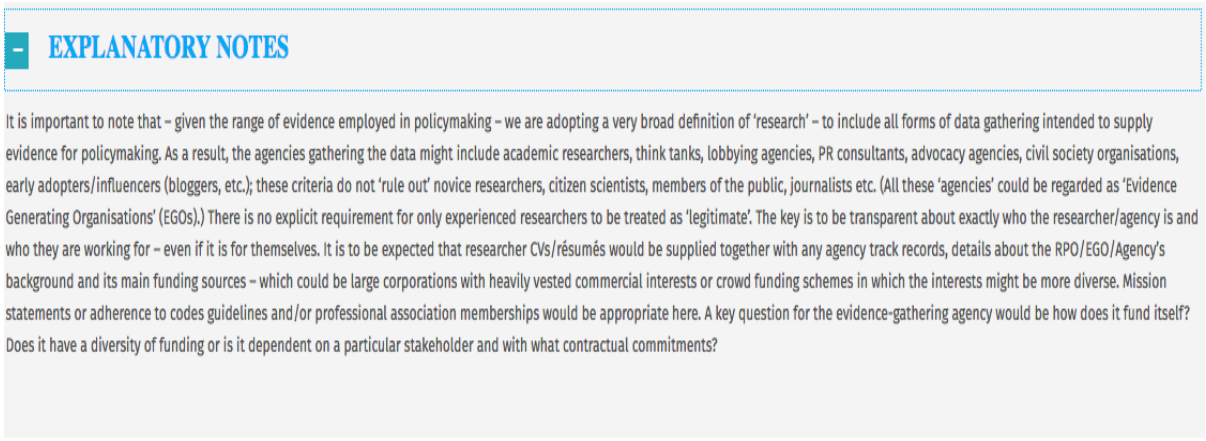
- What are the credentials of the researcher?
- What is/was their competence; experience; track record?
- Who do/did they work for?
- Do they have any vested/conflicts of interest?
- Do they adhere to any specific professional/ethical codes and/or guidelines?
- How was the specific project that generated the evidence in question funded?

Here we have made a distinction between individual researchers and research agencies:

**For the research agency:**

- What are the credentials of the research agency?
- What is their competence; experience; track record?
- Who do/did they work for?
- What kind of research/data-gathering agency are they?
- How is the agency funded/by whom?
- How is the agency governed – how was it founded and with what purpose?
- Does the agency commit to adhere to certain codes/guidelines – does it have a 'mission statement'?
- Does the agency have any vested/conflicts of interests?
- How does it manage data protection regulations?
- How was the specific project that generated the evidence in question funded?

With each set of questions we have supplied explanatory notes to make sure that it is clear what we mean by these questions and why they need to be asked:



**EXPLANATORY NOTES**

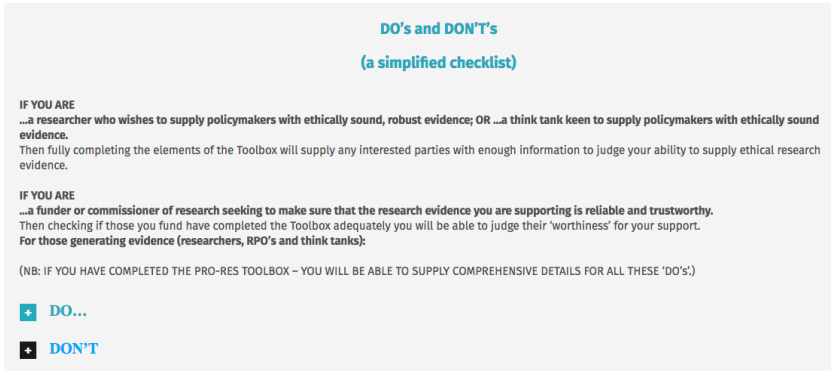
It is important to note that – given the range of evidence employed in policymaking – we are adopting a very broad definition of 'research' – to include all forms of data gathering intended to supply evidence for policymaking. As a result, the agencies gathering the data might include academic researchers, think tanks, lobbying agencies, PR consultants, advocacy agencies, civil society organisations, early adopters/influencers (bloggers, etc.); these criteria do not 'rule out' novice researchers, citizen scientists, members of the public, journalists etc. (All these 'agencies' could be regarded as 'Evidence Generating Organisations' (EGOs).) There is no explicit requirement for only experienced researchers to be treated as 'legitimate'. The key is to be transparent about exactly who the researcher/agency is and who they are working for – even if it is for themselves. It is to be expected that researcher CVs/résumés would be supplied together with any agency track records, details about the RPO/EGO/Agency's background and its main funding sources – which could be large corporations with heavily vested commercial interests or crowd funding schemes in which the interests might be more diverse. Mission statements or adherence to codes guidelines and/or professional association memberships would be appropriate here. A key question for the evidence-gathering agency would be how does it fund itself? Does it have a diversity of funding or is it dependent on a particular stakeholder and with what contractual commitments?

You can do this with any of the main questions.

Give it a try.

We have also supplied these key questions in the form of a 'Do's' and Don't checklist.

One for researchers and funders:



**DO's and DON'T's**

**(a simplified checklist)**

**IF YOU ARE**
**...a researcher who wishes to supply policymakers with ethically sound, robust evidence; OR ...a think tank keen to supply policymakers with ethically sound evidence.**
Then fully completing the elements of the Toolbox will supply any interested parties with enough information to judge your ability to supply ethical research evidence.

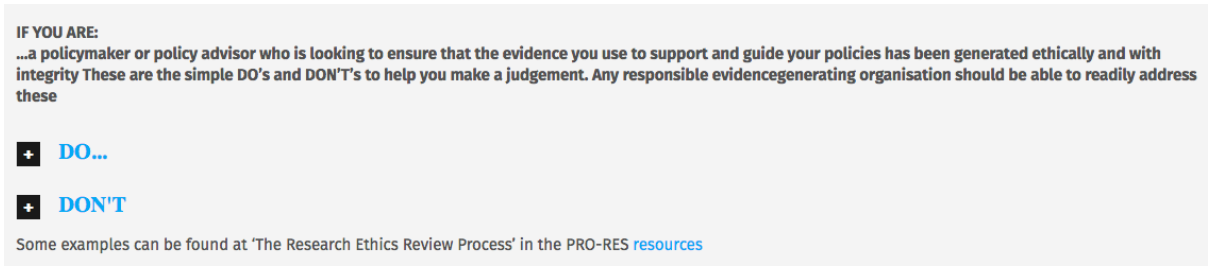
**IF YOU ARE**
**...a funder or commissioner of research seeking to make sure that the research evidence you are supporting is reliable and trustworthy.**
Then checking if those you fund have completed the Toolbox adequately you will be able to judge their 'worthiness' for your support.
**For those generating evidence (researchers, RPO's and think tanks):**

(NB: IF YOU HAVE COMPLETED THE PRO-RES TOOLBOX – YOU WILL BE ABLE TO SUPPLY COMPREHENSIVE DETAILS FOR ALL THESE 'DO's'.)

DO...

DON'T

and one for policymakers and their advisors:



**IF YOU ARE:**
**...a policymaker or policy advisor who is looking to ensure that the evidence you use to support and guide your policies has been generated ethically and with integrity These are the simple DO's and DON'T's to help you make a judgement. Any responsible evidencegenerating organisation should be able to readily address these**

DO...

DON'T

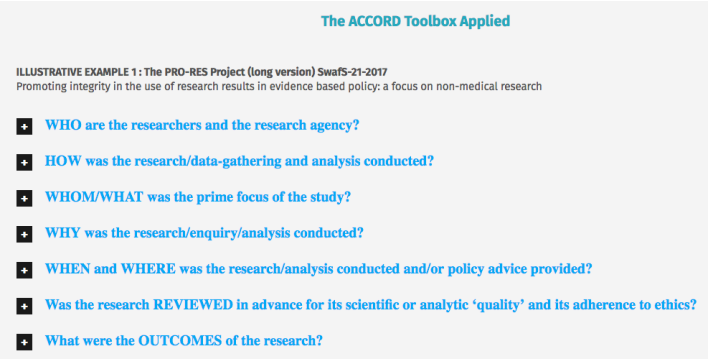
Some examples can be found at 'The Research Ethics Review Process' in the PRO-RES resources

Open these out to see how easy they are to use:

## DO...

1) ...ask for details about the researchers/research agency conducting the research.
2) ...check the researcher/agency's ability to conduct the research: competence, credentials, education and training.
3) ...review any track record: look at their previous work.
4) ...clarify their funding sources.
5) ...identify any vested interests or conflicts of interest they may have.
6) ...check the ethical codes and guidelines they claim to follow.
7) ...check if they are signatories to the PRO-RES Accord or other statements of research integrity.
8) ...explore their ideological and/or theoretical bases and how that might influence their products/services.
9) ...examine their data management procedures and legal compliance.
10) ...check out the specific research methods or data gathering procedures they employ.
11) ...examine their methods of data collection and analysis for any specific evidence they are offering.
12) ...discover how they dealt with potential biases.
13) ...ask for detail about how they treated any subjects they studied.
14) ...seek an account of what they see as the benefits and/or impact of their work.
15) ...check out how they deal with any unintended consequences of their work.
16) ...look at how they report or disseminate their work.

We have also offered some examples of how the Toolbox might be applied or operationalised:

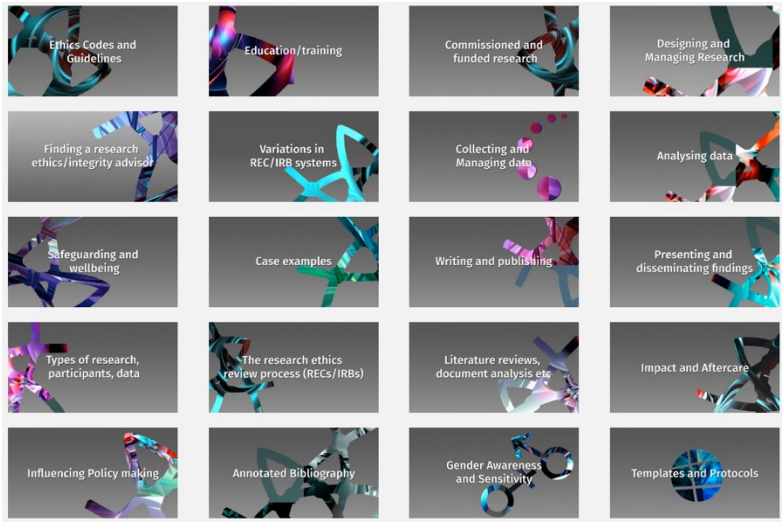

The ACCORD Toolbox Applied

ILLUSTRATIVE EXAMPLE 1 : The PRO-RES Project (long version) Swafs-21-2017
Promoting integrity in the use of research results in evidence based policy: a focus on non-medical research

- WHO are the researchers and the research agency?
- HOW was the research/data-gathering and analysis conducted?
- WHOM/WHAT was the prime focus of the study?
- WHY was the research/enquiry/analysis conducted?
- WHEN and WHERE was the research/analysis conducted and/or policy advice provided?
- Was the research REVIEWED in advance for its scientific or analytic 'quality' and its adherence to ethics?
- What were the OUTCOMES of the research?

We will be looking for more of these and welcome some from consortium partners.

In addition to the Toolbox we have supplied a comprehensive set of resources that can be used to implement the Toolbox, to support researchers, funders and managers, but also resources that could be used by policy makers or their advisors.




Here we would welcome any suggestions about the categories we have offered – changes or additions. But within the categories we welcome suggestions for elements that will enhance the resources already on offer.

Let's say a policymaker wants some advice from experts in the field. Go to:


and scroll down to illustrate.

Alternatively let's say a researcher wants information about training:


Now we could spend some time looking in detail at other resources boxes – but let's just point out a couple of other useful sources of information.

We have supplied a glossary of terms so that all can be clear on the concepts, definitions and terms we are using:


The glossary has been updated in response to suggestion about changes in definition and terms we missed out. But we welcome more comments and suggestions for additions.

Finally, for now, we have brought all the references we used in writing and researching the issues involved in constructing a Framework such as this in an annotated bibliography:


It is annotated to help people find the kind of source material they will find useful – rather than everything that is available in the field – which can be daunting and confusing.

That is a basic introduction to the PRO-RES Framework that should help you make best use of it.

We would be delighted if you could sign up to Accord and, at the very least, recommend our approach to your network of colleagues.

We welcome your views and opinions that might help us improve what is on offer.