Productive Margins

DATA MANAGEMENT FOR CO-PRODUCED RESEARCH

Susy Giullari **'In collaboration with the Productive Margins Collective'**

July 2016

HAMILTON HOUSE

SCDA

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

BBS Development Trust

Building the bridge
A Muslim community conference for everyone

University of BRISTOL

KWMC
KNOWLE WEST MEDIA CENTRE

Cardiff Communities First
Cymunedau yn gyntaf Caerdydd

SPAN

E·S·R·C
ECONOMIC & SOCIAL RESEARCH COUNCIL

ACKNOWLEDGMENTS

Encountering a load of data management obstacles **Productive Margins** decided to employ me to find some solutions. I want to thank them for having given me the opportunity to study what has emerged to be a fascinating and important issue. It is thanks to that decision and to a fruitful workshop that we ran with all the program members this September that this guide was produced. We hope this guide will be of use to others engaged in co-produced research.

We also want to thank a number of people from Bristol University, Emma Williamsons taking a keen interest from an ethics committee point of view, Caroline Gardiner from the research data depository, Stephen Gray from the Research Data Service and Liam Mckervey from Research Governance and Ethics for their invaluable cooperation.

We are grateful to the ESRC for funding **Productive Margins-Regulation for Engagement** research programme.

Visit http://www.productivemargins.ac.uk/

E-mail: susannagiullari@yahoo.co.uk

ABOUT THE MAIN AUTHOR

Dr Susy Giullari is a Research Associate with **Productive Margins-Regulation for Engagement,** University of Bristol. She has a PhD in social policy. Her research interests are co-produced and participatory research methods, cross-national methodologies, family policy and feminist theory on citizenship and welfare. She has worked as a researcher for a number of years in academia and community research in cross-national and co-produced research projects. Publications include **Giullari** S. (2007) *Proofed for Parents by Parents: Participatory One parent Proofing: Findings*, Bristol, SPAN; Taylor, Cohen; Lewis, J and **Giullari**, S (2005) 'The Adult Worker Model Family, Gender Equality and Care: The Search for New Policy Principles and the Possibilities and Problems of a Capabilities Approach', Economy and Society 34 (1): 76-104*;* **Giullari**, S. and Shaw, M. (2005) 'Supporting or controlling? New Labour's Housing Strategy for Teenage Parents', *Critical Social Policy* 25 (3): 402-417.

CONTENTS

FIGURES AND TABLES

[1] Adapted from UKDATA service

INTRODUCTION

What is research data?

This is the first question to answer. It is often difficult to establish what part of our data is *research data* and if the project is multidisciplinary, or generates different forms of data it can be even more complex. So it is useful to continue discussing this at different stages of the project. The following statements might help.

- Research data can take any form: photos, text, objects, numbers, drawings, videos etc.
- Research data and outputs are not the same thing
- Research data is generated for the purpose of analysis

What is research data management?

Data management is not a distinct element of research, it is part and parcel of the research process. Corti and Bulgor (2014) data managements has made up of different stages that happen at different phased of the data life cycle. In figure 1 we have adapted their vision to a co-produced research scenario.

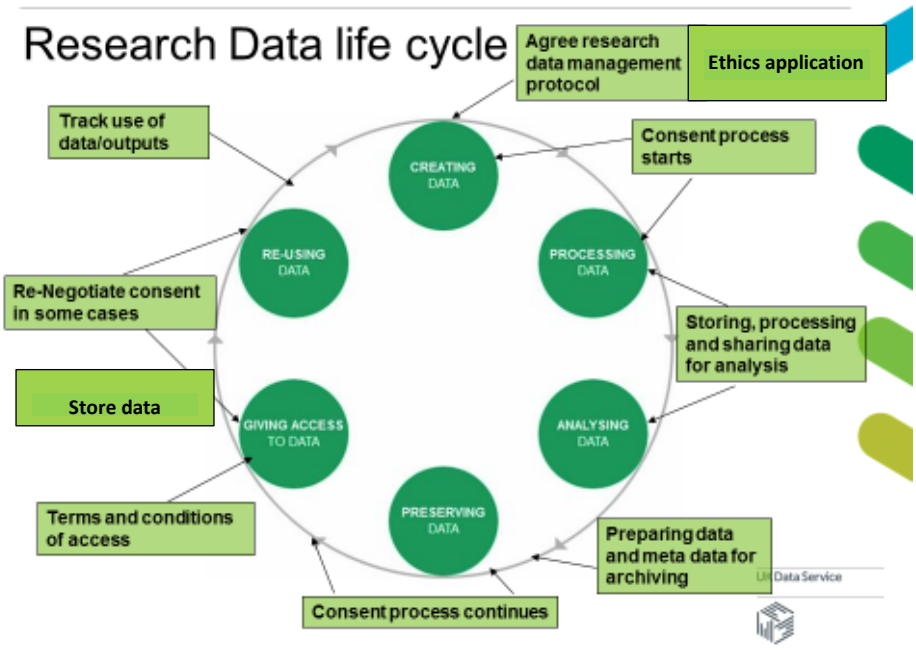
The main stages are:

- Data Management Plan[2] and Ethical Application
- Gaining Consent for using and re-using data
- Storing and processing data for analysis
- Preparing data for storing and sharing
- Storing data
- Reviewing and tracking access requests
- Outputs

Figure 1- Data management within the research data life cycle[3]

[2] Data management plans get modified as the research begins and unfolds. Recognising the principal tensions that we are likely to encounter and the need for a flexible approach to deal with them.

[3] Adapted from Corti and Bulgor (2014)



ADAPTED FROM UKDATA SERVICE

PHASE 1: DATA MANAGEMENT PLAN AND ETHIC APPLICATION

Step 1 Discuss co-produced research data management puzzles

You might have already developed a data management plan for your funding application. Still once partnerships have been formed it is worth dedicating some time to discuss the expectations, priorities and capacities that partners hold in relation to data management. It is equally important to make everyone aware of the regulatory frameworks that regulate research data management such as the Data Protection Act (1998)[4], copyright issues, institutions' ethical guidelines, grant conditions for storing data; choice of data depositary and sharing procedures within the project and with the public.

Step 2 Discuss ethical issues specific to co-produced research

Ethical applications for co-produced research could consider the followings:

- Internal confidentiality- organisation and community level
- How to gain consent for archiving in a variety of institutions
- Consent for sharing data for further use, i.e. not just research

[4] See Charlesworth, A. (2014) Data Protection and Research Data, JiSC Digital Guide

Co-production can entail additional ethical issues, or indeed complicate the balancing of different ethical issues. As a PM members argued *"Who are we to close down people's stories? But it is never as simple as that, we also have a duty of care.* So we acknowledge this tension in our research practice."[5]

Co-production research is committed to the principles of mutual respect, and it is more common for participants to want to be named in outputs, and in data to be shared. Young people in particular can be so used to publish on social media that they cannot see the point of anonymity. Participants might also dip in an out of anonymity at different stages of the research process. At the same time we have to consider how that might affect the other participants and the community organisations involved. When producing visual data, or in public events and festivals it is often impossible to guarantee anonymity. Still we have to protect individual's right to be visible and/or have a platform, and make sure we have their consent for storing and sharing that data holding their personal identifiers.

Gaining consent in co-produced research is best seen as a process that takes place throughout the research, so that participants can be informed about the implications of generating, processing, storing and sharing data. With the storing and sharing of data gaining consent can become more difficult, particularly if there is not much time. If consent is gained through signed forms, you have to add an extra paragraph or two, making the information sheet and the forms rather long. There is a risk here that the participant will switch off, loose interest. This risk can be bigger when doing co-produced research with users of community organisations who are deeply trusted and respected by the participants. What's more the question of time is particularly problematic. People might purposely want to be visible today, for a number of reasons. But this might not be the case in 10 or 20 years' time, when their lives, aspirations, values etc. might have changed significantly. A regular quote on face book is "*I am glad there was no face book 20 years ago!"* In these cases a process approach backed up by singed sheets might be more appropriate.

Case study: gaining consent for sharing data

I[6] encountered issues with gaining informed consent from vulnerable people, or people who may lack capacity. Gaining consent in these circumstances is more complicated, but especially with the added layers necessary for the new requirements to store data for 20 years, and the possible use by other projects. I felt it was difficult to explain why data might be shared, and how data might be used. Many of the people I interviewed did not have a good understanding of research, Universities, how research happens, bureaucratic processes, risk, safeguarding,

[5] Comments in Italics are from PM members who participated at the Productive Margins Data Management Workshop, 2015

[6] This is the voice of one of PM community researchers, who has a PhD in social sciences.

confidentiality and anonymity. In some cases, I thought that trying to explain these concepts to participants might damage the fragile research relationships. Perhaps a prerequisite for gaining this consent from vulnerable groups or in communities where they may be suspicion of researchers, needs to a well-established research relationship. In cases where I attempted to get informed consent for the higher level of storage but felt I could not guarantee that the person had understood the implications, I wrote this up in the documentation to ensure this would be taken into consideration.

Info sheets and consent forms[7] could potentially include information about the following: risks attached to identification to individual, community and organisations involved; what depositary are; a list of possible data depositary including those of community organisations; how the data could be re-used for to including community organisations' activities; process of anonymization and access control**;** timing of storage 20 years+.

Here are also a **few useful techniques**:

- Explore with participants the risks of non-anonymity at different times and stages of the research
- Explore with participants the risks of non-anonymity today, tomorrow and in 20 years' time
- Explore with participants the risks of their data being made public on the internet. Remind them that on-line tools may by default collect 'sticky data' of background information such as data logs, cookies
- Explore with participants the dangers that one person's refusal can imply for the other participants/community
- Take into account internal confidentiality i.e. between groups, community organisation and Universities
- When generating video data consider the implications of recognising places for communities and individuals[8].
- When recording, taking pictures or videos at public events, make participants very aware about where and how you plan to store and share them. You can put up posters, introduce the issue at the begging of the event, put in the publicity material and website.
- Storage and sharing**:** talk to participants about how the data will be stored and kept safe, and ask them whether they would like their data to be openly available or not and for what purpose. The data will be stored in a safe university storage, and it could be openly shared or restricted to particular use or people.

[7] Please find the information sheets and forms that we have used in Productive Margins in the appendix

[8] Van den Eyden et al (2015) suggest a 3 stage process for visual data: gain consent to be filmed, then to participate in the video creation and finally consent to share the film.

- Track consent when consent is obtained at various stages of the research through dialogue and rapport, it is important to have an 'audit trail' to show when and how consent was obtained. Without this it will not be possible to make any decisions on what can be done with the data, whether it can/should be anonymised, and any conditions attached to long-term storing or sharing.
- When artists or facilitators have been commissioned[9] make sure they are aware of the ethical guidelines and that they gain consent and follow consent when re-using and sharing data.

Step 3 Identify ethical principles to address for institutional relations

Data management is strictly linked and to some extent bound by a set of ethical guidelines and an ethical review process. These vary according to disciplines and institutions. In co-production we can encounter different ethical principles held by community organisations or other institutions. It is important to discuss these different ethical principles and to include some principles that ensure inclusion and mutual benefits for all partners. In Productive Margins we have used the following[10]:

MUTUAL BENEFIT, EQUALITY AND INCLUSION, MAKING A DIFFFERENCE means that PM partners could have a right to:

- **Co-Stewardship of research data, including reviewing of requests at controlled level**
- **Automatic access to data stored in for all partners**
- **Co-Data storing**
- **Shared copy-right**
- **Collaborative Authorship**
- **Re-use of data to include community impact, engagement and community work**

Step 4: Nominate a dedicated person[11]

- Oversee to oversee all confidentiality procedures
- Ensure that all project members adhere to legal and ethical regulations

[9] See contract section for more information
[10] These principles are taken from Connected Communities and Know Your Bristol recommendations.
[11] Van den Eyden et al (2015)

PHASE 2: STORING, PROCESSING DATA FOR ANALYSIS

This stage of data management analysis is very important for a number of reasons. First this allows us to make sure that data is secure, avoiding any data loss or breach of legal requirements, and the consequential financial and reputation risks. Second in co-produced research data management is a process of giving assurance to individuals and communities that their data is stored safely. Third, establishing secure data management at this stage can ensure that data can be co-analysed.

STEP 1: CHOOSE THE DATA STORAGE

There are various ways to store and share data securely for the purpose of co-analysis. It is not safe to store data on local data storage (PC's own drive, memory sticks, CDs). Some Universities provide **Virtual Research Environments,** but these often require significant set up and maintenance and are usually mono-institutional[12], therefore not lending themselves to co-production

Most Universities have their own cloud drive, which is not be confused with cloud drives open to all. These drives are very useful because they can be accessed anywhere; very convenient and do good backing. They are run by the Universities IT departments to (a) guarantee security of personal and sensitive data, in line with the Data Protection Act 1998 and (b) to allow co-analysis etc. Some universities like Bristol[13] also have their own storage facilities, specifically developed for storing data, which allow for collaboration with other institutions and organisations.

Some partners' organisations may employ the researchers directly and it in this case they may wish to store the data in their offices. In this case it is important to remember to encrypt the data every time it is shared via e-mail or by stick. It might also be sensible to sign a Joint Data Controller agreement as per DPA (1998).

STEP 2: Keep the data safe

The data should never be copied into a non-University PC drive, file or local computer drive or machine, or sent by email without encrypting. If this happens the data is not safe anymore, as it is not in a University controlled drive.

It is not safe to store data on local data storage (PC's own drive, memory sticks, CDs) because they are fallible and have very short life span.

There should be no need to transfer this data via e-mail or save it to pen-drives etc. But if this becomes necessary make sure it is encrypted using 7-ZIP. Always send the password in a different way, i.e. if encrypted data is sent via e-mail, send the password via text, phone call.

[12] UK DATA ARCHIVE 'Managing and sharing Data 'May 2011.
[13] Bristol Research Data Storage Facility https://www.acrc.bris.ac.uk/storage.htm

Non-digital storage: for photographs best to use high quality media for long term preservation e.g. acid-free paper & boxes. This will then be kept secure by making secure that access to the room is restricted and password protected, doors are locked.

PHASE 3: STORING AND SHARING DATA

Traditionally data used to be analysed then destroyed, but recently the approach is to value the sharing and re-use of the data. As the Research Councils UK say *"Publicly-funded research data are a public good, produced in the public interest. Publicly funded research data should be openly available to the maximum extent possible"*[14]. There are a number of reasons for storing data. It might be a grant condition, more and more Research Councils require the data to be stored and shared through their archives. Many journals also require access to the deposited data. Researchers all over the world can access the data and engage in secondary analysis. There is also greater transparency for journal readers who can verify such data.

In co-production terms sharing data means that the voices of participants can be heard in a more direct way and by more people. It also means that community partners can access and re-use research data for other purposes, such as supporting funding application, follow-up initiatives and campaigning.

KEY PRINCIPLES

STEWARDSHIP: Data belongs to participants and/or communities. Researchers are stewards with an obligation to care for the data and protect participants'/communities privacy and from harm.

CO-STORING: All partners including community organisations and other universities have a right to store, access and review requests for access. All have to abide to the same data protection and ethical guidelines in their storage and sharing practices.

CO-STEWARDING: A collaborative data board made up of representatives from partners' institutions, including community organisations. To guarantee longevity is best to nominate roles rather than individuals. The board has 3 functions

a. To be the nominated data steward
b. To assign level of access to the data and specify access conditions[15], following recommendations from the projects' researchers and participants' consent
c. Review requests for access of data in the controlled/safeguarded level, in collaboration with data access committees.[16]

[14] RCUK (2015)
[15] For example the board could decide to put the data in the bonafide level of access with the condition that it should not be accessed for certain purposes. They can also ask to see the plan of use for the data request.
[16] The UoB data.bris Repository's Data Access Committee involves projects' members. The UK DATA ARCHIVE guidelines state "*An additional condition may be applied that permission for access needs to be requested from the Depositor".*

KEY SHARING CONDITION: "*Any use of the data must comply with the DPA (1998) and no data can be stored, shared or re-used without the full consent of participants".*

PROCESSES

It is worth noting that all types of data can be stored and shared, ranging from text, numbers, pictures, videos, and artefacts of all kinds. It is possible to digitise artefacts by taking their picture but sometimes this may not be enough for the purpose of further research/use, as one might need to actually touch the object or see it in a real context.

Step 1 Preparing data for storage and sharing this involves two main processes: anonymization and documentation of data. [17] Those researchers who have been most engaged in field work and data generation processes are best place to undertake this task, as they know the data and consent process best. The RCUK stress that funds can be allocated for these kind of task and other related to the storage and sharing of data, and offer a costing tool on their website. It is therefore important to account for these costs when applying for a grant. However we have found very little mention of this in Universities data management guidance, and funders guidelines in general. We think this is a very important issue, which should be made more explicit in the documentations on how to write funding bids. It should also be made explicit that such funds can be shared between academic and non-academic partners.

Anonymization This task should be completed before the data becomes visible to the stewardship data board, because personal data should only be made visible to the least people possible.

- It should be planned well in advance, during data collection.
- Original versions in separate files should be retained, and create a log of all replacements, or aggregations made and store this anonymization log separately from the anonymised data files.
- Remove direct identifiers (name, address etc., vehicle, medical devices identifiers, names of relatives)
- Aggregate or generalise indirect identifiers for example date of birth into age categories; generalise medical information i.e. specific expertise into general medical area. Sex salary, work, education, socio-economic data, household composition, ethnicity, schools, nurseries, dates, times rounding.

[17] The UK DATA SERVICE website has useful guidelines on anomymisation and data documentation. Also very useful are the following guides: Timescapes Anonymization Guidelines, 2008 Bishop and Neal (2012) Data Management for Qualitative Longitudinal Researchers, Guide: 17, ESRC ICPSR. 2012. Guide to social science data preparation and archiving. In.

- Spatial information data needs changing too especially in community studies.

Data Documentation In order to make it re-usable data needs to be clear to possible external users. So the following question should be asked *"What would another user need to know to make sense of this data?* Include the following: inventory of data files; project information (aims/objectives/research questions; description of team make up; description of methodology; dates times; final reports; articles); data generation methods, any relevant contextual information including a description of all involved in data collection (i.e. peer researchers, community researchers, artists etc). Consent process including blank copy of consent forms; tracking of process consent; information sheets; risk factors to individuals and communities. **Include an access** section in which you make recommendations to the data board about which level of control each data set should be held and any specific conditions to consider.

Step 2 Decide where to store the data

The collaborative stewardship board should first check whether one of the grant conditions is to store the data in the funder's archive. Collaborative discuss whether the data should be stored in other depository, for example some universities have their own depository. Community organisations and other partners[18] may also wish to store some of all of the data in their own depository. When discussing where to store the data consider the sharing practices and conditions of each depositary. For example the ESRC ReShare depositary has 2 level of access: open and safeguarded, whilst the University of Bristol Data Research Depositary has 3: open, bonafide researcher and controlled. In the latter data requests are examined one by one by the University data access committee which includes members of the project. Usually those who request data held at some safeguarded level have to provide a data protection plan outlining steps s/he will take to safeguard the data during the project period, along with assurance of their professional identity, organisation details and accurate plan and rationale for the use of the data.

Finally when making a decision as to where to store the data it must be borne in mind that funders do not guarantee depository, as they may follow a process of review which examines the popularity of the project and the potentiality of the use of the data for further analysis. Likewise the data board should aim to maximise the value of the data and evaluate the suitability of the archive, for example whether storing the data directly in the community would increase the likelihood of it being re-used. Obviously all depositories whether they belong to funders, universities or community organisations must follow the same legal, ethical guidelines and practices.

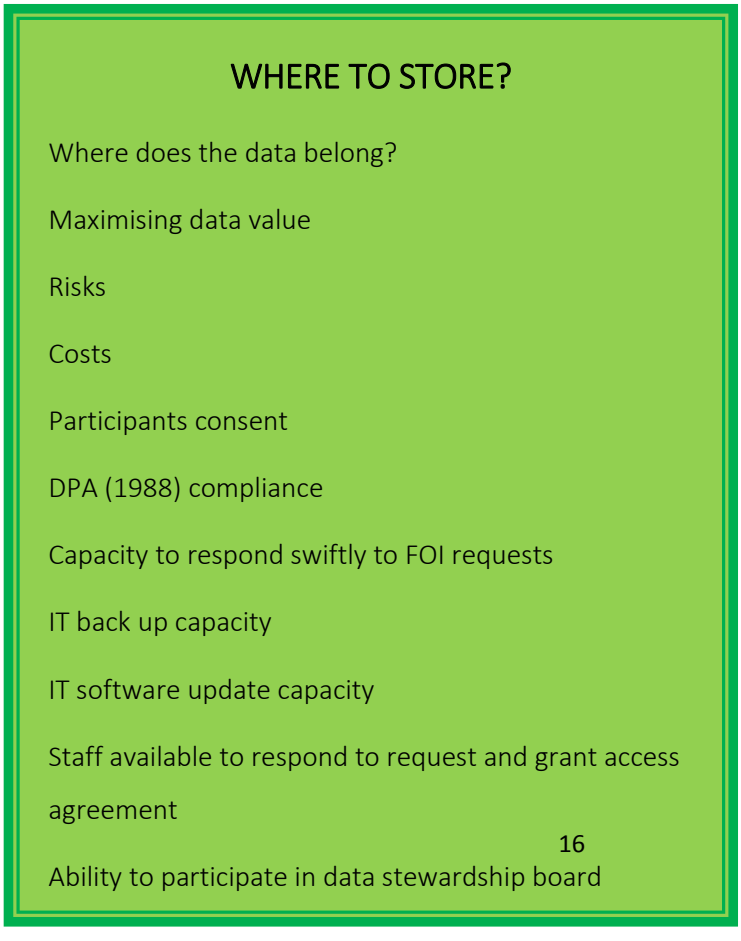
[18] When consider whether they want to store the data partners should consider the following: benefits and costs of data storage; policies and everyday practices ensuring the Data Protection Act (1998); ability to respond effectively and swiftly to Information Requests in line with the Freedom of Information Act (2000); IT capacity to back up the data; ability to engage with the co-stewarding body over a period of 20 years plus.

Last but not least when choosing a depository make sure that the collaborative data board can be included in decision processes about requests for data held at safeguarded levels.

CASE STUDY: Storing data in a community depository

Productive Margins Community Partners took different decisions. They all felt that the data would be useful to themselves and volunteer researchers based in the community, for a variety of purposes such as fundraising, new initiatives etc. However some felt that direct access to a University data depositary was their favourite option as they did not want the burden of storing the data themselves and the costs and risks that this can entail. Others strongly felt that the data belonged to the community where it was generated and therefore it should be stored there. This ethical principle was more important than the associated risks.

Figure 4 Where to store?



Step 3 choose access control levels

Those who have prepared the data for storage should provide the data stewardship board with a set of recommendations regarding access control level and specific conditions. They should also provide a summary of participants' consent on storing and sharing.

Following this information and guidelines as per figure 2 the collaborative board should decide on access levels and conditions.

Figure 5 Guidelines for deciding sharing conditions and level of access control

- Should this data be shared?
- Could this data be useful to others? For what purpose? Further analysis, research? Community development? Reporting? Fundraising? Influencing? Campaigning? Anything else?
- If so with any restrictions?
- Do we have ethical approval?
- Could this data potentially cause harm?
- Is this personal data for which anonymization has been rejected? Will it affect other people's anonymity? Do we have written consent to share it non-anonymised?
- Is this visual data that cannot be fully anonymised? Do we have written consent for s sharing it?
- Who should not access this kind of data? What kind of conditions do we need to specify?
- How long shall it be stored for?
- Can its use/outputs be tracked?

FIGURE 6 Access Levels for Data. Bris.Ac.Uk

OPEN: THE DATA DEPOSITED AT THIS LEVEL IS ACCESSIBLE BY ALL, GLOBALLY, WITHOUT REGISTRATION. DATA MUST BE CITED

RESTRICTED DATA: CREDENTIALS OF APPLICANTS ARE ESTABLISHED AND A DATA ACCESS AGREEMENT IS SIGNED BY AUTHORISED SIGNATORY FROM REQUESTING INSTITUTION. ENCRYPTED DATA IS SECURLY RELEASED.

CONTROLLED CREDENTIALS OF APPLICANTS ARE ESTABLISHED. REQUEST GOES FOR APPROAVAL TO DATA ACCESS COMMITEE, WHICH INCLUDES PROJECT MEMBERS. DATA ACCESS AGREEMENT IS SIGNED BY AUHTORISED SIGNATORY FROM REQUESTING INSTITUTION. ENCRYPTED DATA IS SECURLY RELEASED.

PHASE 3: CONTRACTS AND OUTPUTS

CONTRACTS

Data management is strictly related to outputs and copyright issues. It is important to discuss issues of authorship and copy-right from the start when partnerships are being established.

At present Universities contracts may or may not be specifically designed to take into account co-produced research partnerships. It is therefore very important to make sure that before signing contracts all partners are happy with the copy-right, authorship, data storage and access stipulations.

Often in co-produced research the Universities control the main budget and community organisations are allocated a particular sum to carry out research. Sometimes external free-lancers are commissioned to do specific pieces of work, such as artists. Contracts need to reflect the co-produced nature of the research.

So for example when funds are passed on to community organisation to carry out research and/or employ researchers, they must state that the copyright to outputs **and to data**, its stewardship and storing, will be shared.

Likewise when commissioning contracts must state that copyrights are shared between those that have produced the data and outputs, and that each party is equally allowed to make non-commercial use of data and outputs providing that they have the research participants consent to do so.

CASE STUDY: A commissioning contract for co-produced research

Productive Margins commissioned a number of artists. We wanted to make sure that artists could use the outputs and data they help to produced whilst at the same time safeguarding participants' and communities, and also making sure that all organisation involved maintained copy-right. We worked with the University contract's team to devise a couple of new sentences in the contract.

Copyright and ownership: The results of the work, data and outputs, will be jointly owned by [....]..... Each, as joint owner, may deal with and exploit those results as though it were the sole owner, without being required to account to the other for any share in revenues generated by that dealing or exploitations, provided that neither may disclose to any third party or grant any third party any rights that detract from the other's right to deal with any jointly owned results.

5. Privacy and Ethical guidelines: Any use of the data and output by any of the parties above must comply with the Data Protection Act 1998 and ***Productive Margins ethical protocol main principle which is that no data/output can be shared, published, or archived without the full consent of the participants.***

OUTPUTS

One way to address co-authorship is to adopt the principle of a hybrid model for acknowledging contributions to programme outputs. Assuming that many people will be involved in the production of outputs and wanting to acknowledge this, a case by case approach can be used to account for the range of outputs and their publication, performance, exhibition, contexts.

The coproduction of outputs will be negotiated as part of the process and acknowledged through formal attribution, footnotes, acknowledgements, abstracts, Executive Summaries, exhibition notes, etc.

The Ethical Review Application needs to include a statement about outputs protocol.

Guidelines

FOR JOURNAL PUBLICATIONS, BOOK CHAPTERS, PRACTICE AS RESEARCH OUTPUTS:→→ significantly contributing authors/creators to be listed as Co I's / major author(s), with acknowledgement 'in collaboration with the [....] Collective.'

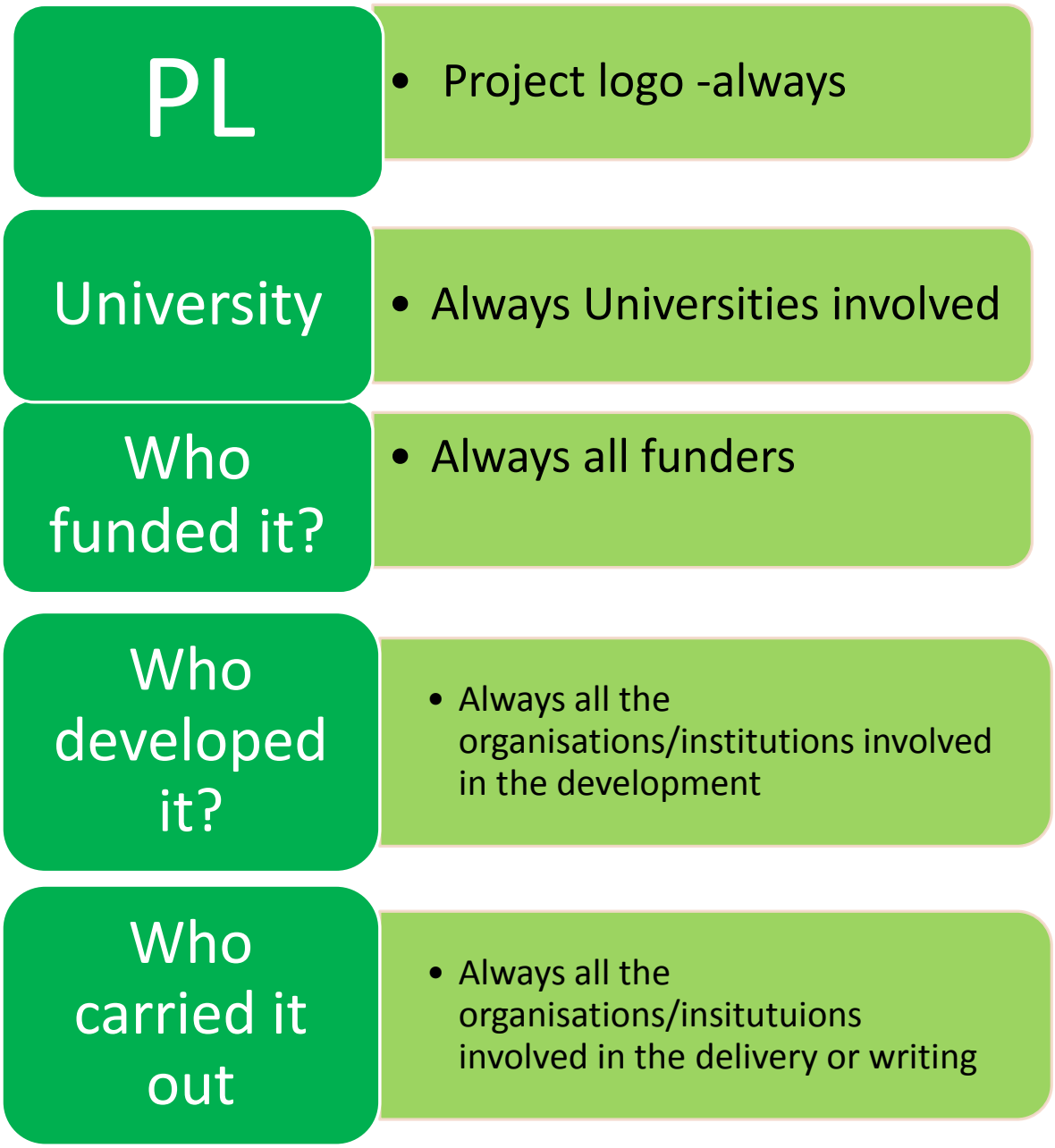
BRIEFING PAPER(S) all authors to be listed as research project team with an acknowledgement of [....] Collective

OTHER OUTPUTS A wide range of activities may not fall under the definition of 'research', including reports, teaching/training toolkits, digital media, installations, art, performance, digital and broadcasts, apps, exhibitions, novels, play, poetry, music, films, curatorship, artefacts.. Any print materials to →→ acknowledge contributors/creators (community members, academic researchers, artists) 'in collaboration with the [.....] Collective'.

LOGOS

The [.....] collectives needs to acknowledge funders and partners by publishing their respective logos 1 in websites, publicity and outputs. Given the number of partners working on different projects sometimes it can be difficult to decide which logos to include so use your good judgment bearing in mind the following questions:

FIGURE 8 which logo?



REFERENCES

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A., Moore, N., Nayling, N., Stokoe, A. and Strachan, A. 2013. Everyday ethics in community-based participatory research. *Contemporary Social Science*, **8**, 3, 263-277.

Centre for Social Justice and Community Action (2012) Community-based participatory research. A guide to ethical principles and practice https://www.publicengagement.ac.uk/sites/default/files/publication/cbpr_ethics_guide_web_november_2012.pdf

Charlesworth, A. (2012). "DATA PROTECTION, FREEDOM OF INFORMATION AND ETHICAL REVIEW COMMITTEES." Information, Communication & Society 15(1): 85-103.

Charlesworth, A. (2014 (updated 2015). Data Protection and Research Data Digital Guides. JiSC https://www.jisc.ac.uk/full-guide/data-protection-and-research-data

Corti, L. (2014) Managing and sharing research data. RMF. Oxford, UK DATA Service.

Digital Curation Centre (2014). Five Steps to decide what data to keep http://www.dcc.ac.uk/resources/how-guides/five-steps-decide-what-data-keep

Durham Community Research Team (2011) "Community-based participatory research: Ethical challenges." http://www.ahrc.ac.uk/documents/project-reports-and-reviews/connected-communities/community-based-participatory-research-ethical-challenges/ Retrieved October 10: 2012

ESRC (2015). Research Data Policy http://www.esrc.ac.uk/funding/guidance-for-grant-holders/research-data-policy/

ICPSR (2012) Guide to social science data preparation and archiving, http://www.icpsr.umich.edu/files/ICPSR/access/dataprep.pdf

Know Your Birstol,. "A Participatory Heritage Mapping Toolkit for Researchers and Communities." http://knowyourbristol.org/resources/

Markham, A. (2012). Ethical Decision-Making and Internet Research- Recommendations from the AoIR Ethics Working Committee USA.

Media, J. D. Copyright and Still Images: Frequently Asked Questions. Digital Guides

MIQDAS On-Line guide methodological issues in qualitative data archiving and sharing: the guide, Cardiff University http://www.cardiff.ac.uk/socsi/hyper/QUADS/guide.html

Neale B. (2012). Data Management for Qualitative Longitudinal Researchers, Timescapes Methods Guides Series

Quigley, D. (2006). "A review of improved ethical practices in environmental and public health research: case examples from native communities." Health Education Behaviour 33(2): 130-147.

RCUK (2015) Guidance on best practice in the management of research data http://www.rcuk.ac.uk/documents/documents/rcukcommonprinciplesondatapolicy-pdf/

Rivers CM and Lewis BL. (2014). "Ethical research standards in a world of big data [version 1}." F1000Research 3(38).

Social Sciences and humanities research ethics special working committe (2008). Research Involving Creative Practices: A Chapter for Inclusion in the TCPS. Ottawa, Canada Interagency Advisory Panel on Research Ethics. http://www.pre.ethics.gc.ca/eng/archives/policy-politique/reports-rapports/ricp-ripc/

UK DATA ARCHIVE (2011) Managing and Sharing Data- Best Practice for Researchers, http://www.data-archive.ac.uk/media/2894/managingsharing.pdf

University of Bristol. Managing Research Data https://data.blogs.ilrt.org/

University of Bristol (2015). Ethics of Research policy and Procedures http://www.bristol.ac.uk/media-library/sites/red/documents/research-governance/research_ethics_policy_v6_220515%20FINAL.pdf

Wiles, R., et al. (2008). Visual Ethics: Ethical Issues in Visual Research. ESRC National Centre for Research Methods Review Paper, NCRM http://eprints.ncrm.ac.uk/421/1/MethodsReviewPaperNCRM-011.pdf

Williams, M. Dicks., B. Coffey, A. and Mason Bruce (??) Qualitative data archiving and reuse: mapping the ethical terrain. Briefing Paper 2.
http://www.cardiff.ac.uk/socsi/hyper/QUADS/Briefing%20paper%20ethics.pdf

APPENDIX 1: INFORMATION SHEETS AND CONSENT FORMS

IT IS PARAMOUNT THAT EACH PROJECTS GAINS FULL INFORMED CONSENT FROM THE PARTITICANTS ABOUT SHARING AND ARCHIVING, FOR ETHICAL AND LEGAL REASONS.

How do we gain consent for archiving and sharing in co-produced research?

Information sheets

Participants information sheets should specify that once anonimised the data will be archived and shared. They should explain

- What an archive is: *An archive is a secure place where different types of materials are stored and looked after indefenitately.*
- The list of possible archives/ redepository including those held in partners' organisatios (community, statutory etc.)
- Benefits of archiving data: transparency, secondary research, citizens can access it etc.
- Explain that all data will be anonimised for individuals and places, unless the participants explicitly asks to be nominated in the data.
- Explaing that sensitive data might be shared following a vetting process
- Copyright: explain that all partners are data stewards which means that they have access to the data, after anonymisation, they can store it and share it, if the maintain anonymity and also have the participants consent to do so.
- What the data could be used for: it is difficult to predict all the ways in which the data will be reused, so make this clear and give a few examples: research; fundraising, development, campaigning
- Stress that this data might be stored for 20 years or more. Hence it is important to think of the implications of what you say today for your future.
- Clarify that data takes text and visual, artefact forms and all of this will be archived.
- Gain consent for the sharing and archiving of unaltered visual data. Explain that altering such data is not always possible and does not neccessarly guarantee anonimity, very labour intensive and expensive.

Example of paragraph for information sheet

1. ***Will you tell anyone what I say?*** *Everything that you say will be kept confidential. It will go into an archive so that people in the future will be able to understand the lives of young people at the turn of the millennium. Your identity will be protected at all times.* • ***What will you do with the photographs, and other visual materials?*** *Also your drawings and photographs will be stored in the archive.* You may also want to get a copy of these for yourself. (UKDA[19])

[19] http://www.data-archive.ac.uk/media/198579/ukdaesrcinfosheet.pdf

Examples of consent form

General data

- *I agree for the data I provide to be archived in one of the following archives[20]:*
- *I understand that others will have access to this data if they agree to preserve the confidentiality of the information as requested in this form.*
- ***I do/do not agree** that the Archives….. may use my data without any further approval on my part. It is/is not necessary to contact me again for permission.*

[20] Include partners archives, including community organisations