

Supporting human rights organisations to deliver insights from data: workshop report and outcomes UK Data Service, 29-30 October 2015

Introduction

At the end of October the **UK Data Service** (the Service) organised a workshop on "Supporting human rights organisations to deliver insights from data" at the University of Essex, with support from the Economic and Social Research Council (ESRC). This was in the spirit of the ESRC's ongoing work in [engaging with civil society](#).

For this workshop Human rights organisations were targeted for two reasons:

- First, that Essex is well-recognised in this field, with its well-established Centre for Human Rights and the current University Chancellor, Shami Chakrabarti, who is also director of Liberty, the British civil liberties advocacy organisation.
- Second, data about the people represented by these charities faces particular challenges around privacy and data protection, and hence, wider sharing; challenges that the Service is uniquely positioned to address.

Human Rights organisations attending the workshop included those involved in supporting victims of human trafficking, torture, unfair trials, conflict and war and other vulnerable situations. Speakers from other civil society and philanthropic bodies attended as well as academics and journalists. From the Service's own interest in increasing the amount of data and evidence that can be shared for transparency and analytic purposes, looking more closely into helping provide solutions for safely sharing and utilising data would benefit the broader civil society sector.

The workshop provided a forum for participants to engage with one another to discuss strategies, tools and skills required for civil society organisations to become better knowledge managers. In this context 'knowledge' includes the organisation's own datasets, external contextual data sources and measures of evidence; while 'manager' covers the capacity to handle, report and campaign using this data-based evidence. A wide range of scenarios and data challenges and opportunities were considered, helpfully brought along by the participating organisations. These scenarios covered both legal and ethical challenges of data and their management. Other challenges covered skills and the capacity to maximise the opportunity presented by the data.

Opening session

Louise Corti, Associate Director at the **UK Data Archive** and organiser of this event introduced how the meeting would be organised and set out the interests of the UK Data Service, ESRC's flagship national data investment, in engaging with the data holdings and needs of civil society organisations.

Christina Rowley from the **ESRC** followed by introducing the perspective and investments from the ESRC. She highlighted the data infrastructure they support through the UK Data Service and other projects, and outlined the [What Works Centres](#); independent institutions, part-funded by UK government which aimed to provide robust research evidence for policy and practice in the area of: crime reduction, local economic growth, tackling poverty, early intervention and wellbeing.

Christina went on to describe the ESRC's current Civil Society investments through partnership funding, Centres, such as the Wales Institute for Social and Economic Research, Data and Methods, the new large grant in human rights, big data and technology at Essex, and funding for the NCVO Civil Society Almanac. She mentioned that all ESRC funding opportunities include funding to support collaborative working and knowledge exchange (KE), for example through the standard grants scheme. The KE aspect was important, as it aimed to influence the development of policy and practice, shape legislation, alter behaviour, change concepts and discourses and provide capacity building. Christina finished by highlighting the annual [Celebrating Impact Prize](#) which was a great opportunity for showcasing exemplary policy and practice-related work coming out of ESRC funding.

Neil Serougi, trustee at the charity, **Freedom from Torture**, and co-organiser of this event, provided the keynote speech. He addressed the challenges facing civil society organisations, from changing perceptions of the role that charities should play in society to the current reduced public support for charities, and the challenges they face in navigating a more politicised landscape. He discussed how, by using data more efficiently and effectively, human rights organisations can change people's perceptions of the work they do, and further help the public empathise with the individuals and groups with which charities work. Neil continued by highlighting the problem with the sector's largely 'traditional' use of data to illustrate key performance indicators (KPIs) and producing the kind of reports that are no longer an effective method of demonstrating the impact of their work. There is now a pressing need to use data in a meaningful and intelligent way to both present the outcomes of a charity's work and to help supporters and funders interact with their work.

To conclude and to set the scene for the following two days of debate, Neil left participants with a warning that "the equation of more information with more impact is not necessarily true by default. [So] data is important in the quest to make an impact but, more important in our line of work is being able to make it mean more than the sum of its parts; in other words to deliver more than an array of numbers that usually depict what most of us intuitively would expect to see anyway".

Session 1: In house data collection: what do you have, what do you need and what skills do you have to analyse the data?

Civil society organisations have been collecting increasing amounts of operational, research and evaluation data but with tight budgets and limited capacities; few fully exploit or share the data that they collect. This session, led by **Louise Corti**, aimed to focus on the types of information that organisations collect themselves, identifying barriers to sharing and understanding those data. The session examined what capacity and skills civil society organisations need to undertake good data practices.

Attendees had been asked in advance questions about the data they hold, scope and format, and whether any were shared. Data held included monitoring and evaluation data, qualitative and quantitative, held in a variety of formats; within bespoke customer database systems e.g. Salesforce, spreadsheets, word processing documents, email attachments, SPSS and paper. When asked about data handling and analysis capacity, replies ranged from: in-house software specific skills to input and run queries; in-house analysts in larger organisations; collaboration - drawing on skills elsewhere; and many felt that that they needed more training on issues of storage security, and data protection. When asked about data sharing many did this when: submitting summary data to higher level bodies; reporting to comply with legal requirements; and for analysis purposes where data were transferred to a third party, but typically did not share data for the benefit of others gaining insight. Some saw no need to share data; others might if asked. Issues raised were that: it was not always their data to share; confidentiality

concerns; and international data sharing restrictions. In summary, while some would like to share data, a fair bit of preparatory work would need to be done to make this possible.

All agreed that keeping accurate records in an optimised way, that can be reported upon, offers a solid foundation for demonstrating transparency; complying with both the Information Commissioner with respect to data, and with Charity Commission procedures by providing a record of due diligence to donors.

The session opened with **Tracey Gyateng** from **New Philanthropy Capital (NPC)**, a think tank which helps charities make more use of their data to understand the needs of their beneficiaries, measure impact, plan scenarios and improve operational effectiveness. NPC helps civil society organisations to lever government datasets in order to better understand their effectiveness of their interventions. For example, NPC has been working with the Ministry of Justice to set up the Justice Data Lab, which provides the social enterprise *Blue Sky* with non-disclosive data on the re-offending rates of people who used their services compared to a control group. The data are matched confidentially at the level of the individual by the Justice Data Lab, analysed, and the aggregated results returned to the Blue Sky team. NPC are also working with the Department of Work and Pensions on a similar scheme focused on employment outcomes. By providing quantified data on whether people who have used a charity's services are more likely to avoid committing further crimes or return to employment, this mechanism gives charities an evidenced measure of the 'hard outcomes' of their activities.

Tracey outlined a number of barriers charities face sharing their data or using external information sources. Consent can be an issue; vulnerable, hard-to-reach groups may be reluctant to give consent for their data to be shared with government departments. Charities may also be unaware data are available, unable to spare the time or money to invest in data, lacking the skills to analyse data or understand the results, worried about what the data may tell them, or concerned about privacy and ownership. The importance the future role of the national services like the [Administrative Data Service](#) in providing safer and easier access for civil society organisations to government data was stressed.

Nigel Fielding of the **Department of Sociology** at the University of Surrey used the prison reform charity the [Howard League](#), with which he has worked for many years, to illustrate the rich and deep information resource that a charity could offer. The League's information base goes back to the 18th century and spans original pamphlets and tracts as well as surveys documenting parliamentary processes and policies relating to prison reform. As an operational campaigning charity, this information base continues to grow and has great potential for academic researchers. However, the League has few resources to systematically organise the materials it holds in a way that would make them easier to discover and share. Although only a fraction of the League's materials held are in digitised form, Nigel emphasised the power of computer assisted software qualitative software (CAQDAS) packages in managing textual and visual information in order to help civil society organisations to leverage information resources in order to advance their agendas. The CAQDAS Networking Group that he set up in the 1990s can offer support for organisations in choosing software and training in how to exploit their features. Nigel highlighted the useful role of involving students in the work of the League through placements, who are incentivised by the direct experience they gain from criminal justice work by undertaking office work but also getting directly involved in campaigns. This work experience includes going into prisons on fact-finding missions to talk to prisoners about the League's work, and meeting with prison governors and staff to discuss policy and practice. Students also prepare briefings and help draft speeches for the League's senior staff.

In her talk, *Driving a Ferrari into the desert and leaving it there*, **Roisin Read** from the ESRC's Making Peacekeeping Data Work project at the **University of Manchester** spoke of how humanitarian organisations manage security data, in particular relating the conflict and peacekeeping intervention in Darfur. Her research indicates that in conflict situations, data collection guidelines are often not followed in practice, meaning that information is not always gathered in ways that ensure the safety of informants. In Darfur, for example, the consequent fear of reprisals has deterred people from reporting human rights violations or security incidents to UNAMID [the UN-African Union peacekeeping mission in Darfur]. "People stopped reporting incidents ... there was a widespread perception that if you shared information with UNAMID, you would be targeted by the security services."

The talk title derived from a staff member in the information management division of a large NGO who observed that the elaborate and expensive systems for storing, analysing and managing humanitarian field data are simply too far ahead of any desire or capacity to use them. One of the project's interviewees also stressed that in the humanitarian sphere, operational data must be timely. "I need information to be quick and dirty. Good information too late is useless."

The final speaker in this session, **Ingvill Mochmann** of the [GESIS-Leibniz Institute for the Social Sciences](#) in Cologne, spoke about data collection and sharing within an international network for research on children born as a result of war (usually a child whose father has been a member of an enemy, allied or peacekeeping force and mother a local citizen). Although there have been children born through conflict across time and nations, an understanding of their experiences, needs and rights is fragmented and limited. The *Children Born of War* project is a global virtual network that brings together research findings and data collections on the topic. Sources include survey data, administrative data, interviews, letters, photos, medical records, church records, and biographies, in short "everything you can access". The field is very new and a participatory research approach is used to engage older, adult children born of war in the development of questionnaires for younger groups in order include topics and experiences relevant to themselves.

Even as adults, children born of war are often vulnerable, hidden populations. They may be stigmatised and subject to discrimination throughout their lives. This presents a number of practical and ethical challenges including the re-traumatisation of participants and the different ethical regulations of data access, storage and sharing across countries.

Session 2: Making an Impact: Using Data beyond Key Performance Indicators

David Walker, contributing editor at **The Guardian** introduced the session by recommending that a pragmatic approach should be adopted when using data and posed the question, "does a huge amount of data help to promote those in conflicts across the globe?" David continued by suggesting that academics often think "to know, is to do"; and stressed that in order to move forward we need to combine both knowledge and the enterprise of the 'doers' based in civil society, which should forge greater data utility and awareness.

Outlining the work of [Medical Aid for Palestinians](#) (MAP), who partner with the University of Beirut to harness academic analysis, **Bob Jones** demonstrated the value of data in an example where outputs were used by MAP to both raise questions of government, and to provide valuable outputs to government to help inform policy change. Impact is a crucial part of fundraising, with research indicating that donors are more likely to donate around the times during which an event such as a massacre has occurred, when public awareness is heightened. As MAP is largely funded by individual donations, using data to create infographics that demonstrate statistical evidence is key to informing

public awareness. Anticipating public interpretation and understanding of the information has to be carefully managed to avoid any potentially damaging misinterpretations.

Emma Prest told us about how her own organisation, [DataKind UK](#), works. DataKind UK, a chapter in an international network, is a charity that has as its core vision the use of data in the 'service of humanity', creating and nurturing a 'data-for-good' community made up of enthusiastic data scientists. Their work applies data science tools and techniques to social situations and involves putting together teams of volunteer data scientists to contribute to 'Data Dive' events which aim to collect, analyse and visualise data to support better decision making for charities. These hands-on knowledge exchange sessions focus on providing answers to specific questions; bridging the gap between communities and making data owners aware of the rich resources they have available to them.

To emphasise the value of this methodology, Emma outlined a research project where DataKind had worked with an NGO which gives money directly to the poorest villages in Kenya and Uganda. The NGO realised that one of the indicators of poverty was whether there was a thatched roof or a metal roof on the house; a metal roof indicated a richer household and a thatched roof, indicated a poorer household. By using satellite imagery and learning algorithms, DataKind were able to create a model to classify the indicators – metal and thatched roofs – so that those on the ground were able to work more efficiently to identify the poorest communities, enabling the NGO to better manage resources and deliver to villages/communities most in need.

Megan Lucero, Data Journalism Editor at **The Times and Sunday Times**, discussed the reinvention of investigative journalism and its on-going development to demonstrate how computing can advance accountability and public interest in reporting. Using recent scandals on doping within the field of athletics and the corruption within FIFA, Megan outlined the work her team has conducted to ensure the validity of data resources, legal compliance and external evidence to support these 'breaking news' claims and stories.

While collaboration enables us to move forward, combining expertise and data sources to provide support for fundraising and evidence for research and policy change, it is not without its challenges. Data literacy and user engagement with stories has to be carefully managed by the authors/publishers to avoid damaging misunderstanding and misuse of information. Use of incomplete data to publish quickly can also cause harm through exposing unsound findings. Megan demonstrated some engaging interactive visual outputs from her stories that were simple yet effective, allowing the reader to interrogate available data to build up a greater contextual picture of the news item.

Megan spoke of a final caution with 'data-driven journalism': it can lead to the pursuit of topics for which there is available data rather than focusing on topics that need to be investigated! The session highlighted that the effective visualisation of synthesised results and simplified outputs built on solid and robust data can help us tell a story powerfully.

Session 3: Ethical frameworks and governance

The final session of the first day addressed legal and ethical challenges in using and sharing data. **Libby Bishop** from the Service opened the session by summarising the themes that had emerged from case studies, prepared in advance by participants, of the key ethical issues their own organisation were confronting. Key points arising were:

- the dilemma that sharing data may help clients, but also may, in some cases, create risks either to participants or to trust relations with CSOs, even if data protection regulations are fully met;
- the challenges of anonymisation, including understanding legal requirements and finding practical tools to anonymise data;
- how gaining informed consent presented difficulties with some groups, such as children, those lacking capacity, or those who might be retraumatised by relating their experiences of violence.

Libby's spoke on how the Service protects data using its **5 SAFES** framework of **SAFE DATA - SAFE PROJECTS - SAFE PEOPLE - SAFE SETTINGS - SAFE OUTPUTS**, and also shared some practical tools, such as consent form templates that can be used as a basis for designing consent forms.

Jim Vine of the Housing Associations' Charitable Trust (HACT) followed by presenting an example of successful data sharing by a CSO to help its clients through using a 'trusted intermediary'. He described a project called *Community Insight* which leverages the power of information across organisations, providing high-level visualisations to detailed reports on local neighbourhoods. Jim gave an example of where data on low-wage jobs were mapped with local bus routes to reveal a mismatch: jobs were being created in places that were not well provisioned with public transport. As a result, the local community is attempting to provide alternative modes of community transport. Jim went on to present a concise summary of the Data Protection Act and its implications for CSOs. One important point he emphasised was a reminder that not all uses (processing) of personal data must be consented; for example if a CSO can demonstrate a 'legitimate interest' for processing the data and, crucially, there is no 'prejudicial effect' on the individuals' providing data.

To conclude the session, participants worked in groups on ethical issues arising within their own organisations, taking turns to present their situations and getting feedback and actionable suggestions from others. One group had the challenge of gaining written consent from children lacking capacity, with one participant who suggested that audio-recorded might be used to capture consent, but was not sure how to implement this. Others in this group were familiar with the situation and advised that the combination of recorded consent, transcribing the recordings to create a written record, and working with guardians works well. Other problems arising in groups were: how to ensure that a client understands the implications when they agree to having their representation used for campaigning; and how to apply a general risk mitigation strategy when deciding on the level of anonymisation needed for data sharing.

Session 4: Exploring opportunities for using third party data sources to provide context

The first session of the second day examined the potential for using third party data sources to provide broader contextual knowledge for organisations working in the field of human rights. Various forms of data are collected and, often these data can be made available to researchers. Organisations require awareness about how to locate and access these sources and to understand how to evaluate and analyse them. This session sought to answer questions relating to how the strategic goals of CSOs could be achieved by using innovative methods and bringing together different forms of formal and informal knowledge. With the increasing importance of administrative records or 'big data' in this landscape, this session also addressed the theoretical and technical challenges researchers face in trying to analyse these data.

The session began with a presentation from **Hersh Mann** who manages the User Support and User Training area for the Service. Hersh began by providing an overview of the Service and explained that data held and made available comes in different forms - quantitative and qualitative. Illustrating his talk

with examples drawn from topics like housing, poverty, human development, and minority rights, he demonstrated how the Service can facilitate access to data that cover a very eclectic mix of topics. Hersh also explained how the Service assists users in tracking down and helping provide access to data that are not already available. The Service's expertise in how to share data and their trusted relationships with key bodies like government departments and other organisations that create data, can often provide solutions that users may not have thought possible.

Sian Oram from **King's College London**, was the second speaker in this session. Delivering her talk, entitled *Mental health responses to human trafficking: qualitative data tools*, she explained how a current project, [PROTECT](#) – Provider Responses, Treatment, and Care for Trafficked People - she was involved in, aimed to understand how people are identified as trafficked within mental health services, and the challenges professionals experience in responding to trafficked people's mental health needs. She explained that while mental disorder is prevalent among survivors of human trafficking, little is known about health professionals' experiences of identifying and providing care for them. Using the South London and Maudsley (SLAM) NHS Foundation Trust Case Register Interactive Search (CRIS) database, comprehensive clinical electronic health records were used to identify trafficked patients. Content analysis was used to establish how people were identified as trafficked, and thematic analysis was used to explore the challenges experienced in responding to mental health needs.

The final presentation of the morning session was by **Matt Williams and Luke Sloan**, both from **Cardiff University**. Their talk, *Gaining Insights from Social Media Data: Collection, Analysis and Interpretation*, began by showing how they have been using data from social media to understand social reactions to major news stories and how demographic information can be derived from the use of Twitter. They highlighted the enormous growth in the creation of data that has resulted from the use of social media and the potential that these data have in helping researchers interpret social problems.

Introducing the [Cardiff Online Social Media ObServatory](#) (COSMOS), Matt and Luke described a technical architecture for the computational analysis of social media data, and explained the challenges involved in storing and interrogating such large data collections. By using methods such as word frequency counts, network analysis, and geospatial clustering, they showed how they analysed tweets and mentioned how these new forms of information could be used to complement existing sources of data. In the second part of the talk they presented case studies on, for example, cyberhate and the Ebola outbreak. These they used to show how the COSMOS platform allowed them to gain insights into the way information spreads or is not propagated online.

In the final session over lunch participants were invited to discuss issues of their choice with the range of experts present.

Summary

Summing up after such an intensive and positive event like this is easier to say, but harder to enact; we should not let the momentum lapse. Ideas and debates emerged about the way that civil society organisations can work in a data-centric society; what might this mean for the evolution of organisations? The meeting explored very different forms of data, from summary statistics to qualitative classification and social media. In thinking about producing evidence beyond the KPI indicator, there is a need to consider novel ways in which this varied information can be marshalled to influence policy, develop impact strategies or persuade more people to donate.

Even gathering information from participating organisations for the workshop sessions, it became clear that there was an anxiety among participating organisations about the task; and in some cases, the feeling that they might not be able to operate at the level 'expected' from the sessions. What we in the Service very helpfully took away from this meeting was that the formal language of social research can be a barrier to engagement; terms like 'data' and 'analysis' might better be replaced with 'information'; and 'insight'.

In the CSO sector there is less investment, and certainly very few bespoke roles and responsibilities purely dedicated to making information and data work in terms of evidence. It is a truism that many of the participants went back to their jobs the following Monday morning hit by all the mounting work they were unable to do on Thursday and Friday; and it is unrealistic to expect them to become bona-fide researchers with all the skills and the time, the abilities and capabilities.

With less money to upskill staff to undertake research activities, coproduction (with experts on a pro bono basis) is likely to be an important model. More and more organisations need to prove the case for investment in sound and ethical information resources. Good outcomes can help demonstrate this in a feedback loop.

It would be useful for the community to explore the potential to develop a network of organisations that could be better informed and enabled regarding partnership opportunities, such as with ESRC research funding. Another idea for future direction of travel is how the academic community might work up a brokerage system akin to the DataKind model; where university academics can help civic society organisations move to that next level, both in terms of capacity and capability. The national co-ordinating centre for public engagement ([NCCPE](#)) might be the kind of organisation that could help with this. There are platform that already exist within universities that highlight collaboration interests of staff, such as Piirus at Warwick University, designed to match academics with particular interests.

The Service is keen to play its part in helping engage with CSO data issues and this event is our first dedicated initiative in this area. We already have a number of great resources that we can offer, such as running tailored data management workshops and a vast catalogue of data that can be used to provide rich context. There are a number of concrete follow up actions that we can take, within the next 6-12 months:

- run a similar engagement event again next year;
- targeted promotion of our data;
- a stall at the next national Charity Fair or at NCVO's annual 'Evolve' event in June 2016;
- a webinar on introducing useful data sources for the sector;
- a webinar on how to (easily) create data visualisations using free tools such as MS Excel, Google table tools and using the COSMOS social media platform;
- bespoke training and guidance on how to safely manage and share data for organisations collecting data about beneficiaries and leading to the possibility of data deposits that we can curate and provide access to;
- guidance on how to separate legal (i.e., intellectual property, Data Protection) and ethical issues, showing consideration of any possible harm of releasing documents;
- take practical steps to introduce these ideas to the international arena in our work with international data organisations such as the [Research Data Alliance](#).

Presentations and bios from the event are available at: ukdataservice/news-and-events/eventsitem/?id=4128. As the talks were so valuable, edited proceedings will also be available before the end of the year also from this site.

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