Sign Language Translation Mobile Application and Open Communications Framework

Deliverable 9.1: Ethical Guidelines and Protocols

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Acronyms

The following table provides definitions for acronyms and terms relevant to this document.

Acronym	Definition
DHH	Deaf/Hard of Hearing
MT	Machine Translation
REC	Research Ethics Committee

Table of Contents

Table of Contents 4

1. Overview 5

1.1 Research with Deaf communities: ethical underpinnings 6

1.2 SignON - What Needs Ethical Approval? 10

2. Guiding Principles 10

2.1 Research Integrity 10

2.2 Co-constructing our approach 12

2.3 Honest evaluation of what we can do in the time we have available 13

2.4. Publication protocols 14

2.4.1. SignON Adapted CRediT taxonomy 15

2.4.2. Implementation of the adapted CRediT taxonomy 16

2.4.3. Acknowledgements 17

3. Ethics Committee 17

3.1 Scope 17

3.2 Membership 19

3.3 Meeting Schedule 19

3.4 Complaints/Appeals 19

3.5 SignON REC Folder and Email List 20

3.6 Consortium Partner Obligations 20

4. Data Management 20

5. Conclusions 23

References 23

APPENDIX 1: Sample SignON Participant Information Leaflet 25

APPENDIX 2: Sample SignON Consent Forms in International Sign and English prepared by EUD 29

APPENDIX 3: Sample SignON Consent Form for Reuse of Data 33

1. Overview

This report presents guidelines and protocols that will be followed throughout the SignON project. All of our work will be conducted in accordance with the EU Code of Conduct for Research Integrity. This documentation provides guidance and reference for all members of the consortium.

In section 2, we identify key issues that concern us as researchers working with sign languages, including best practices identified for researchers working with Deaf communities, drawing on a range of literature in the field. In any research context, trust between researchers and participants is essential - clearly, given the context we are working in on the SignON project, and given our partnership make-up, we are dedicated to ensuring that we build trust through transparent, engaged, inclusive processes with Deaf and Hard of Hearing (DHH) communities.

The SignON Research Ethics Committee (REC), discussed in section 3, has oversight of the ethical applications that relate to the collection of data from human subjects over the lifetime of the project. This collection includes interviews, focus groups and surveys (including anonymous surveys). Here, we present the practical processes that we operate in the SignON project to ensure that these principles are embedded into our practices, primarily through (i) providing training to all those engaged in the SignON project around issues to consider when working with Deaf communities, and (ii) via the oversight of the SignON REC[1].

We adopt the ALLEA European Code of Conduct for Research Integrity (2017) principles of reliability, honesty, respect and accountability in all we do.

Section 4 discusses our approach to data management. We discuss how we handle and curate pre-existing data sets such as digital sign language corpora and publicly available content as well as new data collected over the life of SignON. We co-reference our Data Management Plan, details of which are described in greater detail in D7.8.

Section 5 presents our concluding thoughts.

[1] A sample Participant Information Leaflet (PIL) and Consent Form are included in Appendix 1 and 2 for reference. Appendix 3 presents a sample Consent Form for Reuse of Data.

1.1 Research with Deaf communities: ethical underpinnings

Wallwork (2002, p.21) argues that "the partnership ideal usefully suggests that our research ethics itself needs to be jointly negotiated and constructed among mutually respectful participants, willing to be changed through dialogue about how to cooperate in joint undertakings." This is an ideal that the SignON consortium takes seriously. At the same time, we are very conscious of the fact that Deaf communities are minority language communities and have experienced suppression of their languages, and, frequently, exclusion on the basis of deafness, despite the existence of legal instruments that consider language rights and/or disability status (e.g. Ladd (2003), Wheatley and Pabsch (2012), Tupi (2019)). Much of this has arisen at the hands of hearing, non-signing policy makers, educators, often informed by hearing, non-signing researchers. In such circumstances, the ideals of partnership, of co-creation, of outcomes, of "nothing about us without us" have not been embraced.

Historically, work has been conducted 'on' Deaf communities and their sign languages by non-deaf or 'hearing' researchers, many of whom have had little knowledge of the community/communities they were seeking to investigate. The associated lack of awareness of Deaf culture(s) has, in some instances, led to research that might today be considered ethically abusive (Harris, Holmes, & Mertens, 2009).

Harris et al. (2009, p.109) advise that when working with Deaf communities, we must consider the importance of respect, beneficence, and justice. They say:

> "…respect is defined in terms of the cultural norms of interaction within the Sign Language community and throughout the hearing and D/deaf worlds. Beneficence is defined in terms of the promotion of human rights and increased social justice. An explicit connection is made between the process and outcomes of research and furtherance of a social justice agenda."

They go on to propose that a Terms of Reference for Academic Research and Publications for researchers working with signing communities is necessary, and outline a Sign Language Communities Terms of Reference (SLCTR) (Table 1) that builds on the Indigenous Terms of Reference (ITR) (Osborne & McPhee, 2000). The authority for the construction of meanings and knowledge within the Sign Language community rests with the community's members.

1. Investigators should acknowledge that Sign Language community members have the right to have those things that they value to be fully considered in all interactions.
2. Investigators should take into account the worldviews of the Sign Language community in all negotiations or dealings that impact on the community's members.
3. In the application of Sign Language communities' terms of reference, investigators should recognise the diverse experiences, understandings, and way of life (in sign language societies) that reflect their contemporary cultures.
4. Investigators should ensure that the views and perceptions of the critical reference group (the sign language group) is reflected in any process of validating and evaluating the extent to which Sign Language communities' terms of reference have been taken into account.
5. Investigators should negotiate within and among sign language groups to establish appropriate processes to consider and determine the criteria for deciding how to meet cultural imperatives, social needs, and priorities.

Table 1: Sign Language Communities' Terms of Reference Principles (Harris et al, 2009: 115) (Adapted from ITR)

The SignON team adopts these principles in our work, and we commit to embedding these in our approach to ethical engagement.

We also adopt the ethical principles of the Sign Language Linguistics Society (SLLS), outlined in their Ethics Statement[2]. This revolves around three key principles:

1. Responsibility to Deaf individuals
2. Responsibility to Deaf communities
3. Responsibility to Scholarship and to the Public

When considering responsibility to deaf individuals, sign linguists are required to be particularly mindful of the right to privacy of deaf consultants/informants/participants. SLLS also points to the fact that " the extra unavoidable dimension of videorecording that makes it impossible to detach the data from the personal identity of the research participant. The rights and wishes of signers with regards to such recordings must be respected at all times."

[2] https://slls.eu/slls-ethics-statement/

The SLLS requires sign linguists to comply with a range of obligations, including the following, which are particularly pertinent to our work on the SignON project:

- Researchers should strive to train Deaf research participants as assistants, research peers, and leaders on research projects.
- The researcher must explain, in an accessible way, the general goals of the intended research before data collection begins (and, when appropriate, the most specific goals after the data collection is completed). If the researcher is not proficient enough in the sign language of the consultant, they must ask for linguistic mediation by another researcher or consultant who is proficient in that language or as a last resort, by a professional interpreter.
- Before starting to work, the researcher should ask for the informed consent of the consultant, either in video version in the relevant sign language or in written form in the ambient spoken language. The second option is dependent on the level of literacy of the consultant in the ambient spoken language, but checking for this creates an asymmetric relation at the start, so the choices should be offered as totally equivalent. Informed consent should not be seen as a formality, but as a way of ensuring that the consultant is aware of all the implications of providing data, of being video recorded, and (when applicable) of the long-term archiving and sharing of the obtained data as well as of the implications of research itself. To this end, the informed consent must be explicit about the setup, duration and number of research sessions, the eventual use and storage of the data once recorded, the possibility of the data being further examined by other researchers on the team, to be included in publications or in presentations at research events, and to be incorporated into data repositories which may have restricted or open access. Special discussion of open access Internet dissemination is important: protection of the identity of the signer in a specific video is impossible to guarantee in that case. To preserve the confidentiality of the signer, they must also be asked whether they consent to having their metadata associated with the data files, as well as being acknowledged by name for their contribution to the research.
- Research results and, where possible, copies of the data itself should always be made accessible to the consultants who participated in the research.

The SLLS also sets out obligations that sign linguists have with regard to Deaf communities. They write:

> “To conduct sign language research, scholars must first and foremost respect the wishes of the signing community, and be careful to involve members of the Deaf community in appropriate

> ways. In the ideal situation, researchers are themselves Deaf; hearing researchers should work with Deaf researchers when possible, including co-authorship as appropriate. Linguists should not always take for granted that their work is by definition beneficial for the communities of signers and should try to explain in a clear fashion what the possible benefit can be of linguistic research on the target sign language. Visibility and recognition of sign languages as natural human languages should be one of the basic targets for the linguistic research undertaken with a Deaf community."

We have adopted this approach across the life-cycle of the SignON project. Additionally, we seek to support SignON researchers in becoming acquainted with the cultural norms and values of the Deaf communities we are engaging with, mediated, in part, by our Deaf community partners. The SignON project has built our consortium around the SLLS principle of engaging with Deaf community organisations from the very inception of this project in considering issues of archiving, distribution of data and where and how research results will be shared, including consideration of the languages of dissemination. Thus, we are considering the macro European Commission goals of Open Science and FAIR data while also considering the ethical and social justice considerations that are important to Deaf communities.

The SLLS requires sign linguists to support the efforts of deaf people to become sign language linguists. SignON has sought to ensure that appropriate deaf applicants know about all available positions that are funded via the project in a bid to support capacity building in Deaf communities and are encouraged to apply for these. We do this because we want to ensure that we have highly skilled deaf researchers on our team. Further, we know that there are very few trained deaf linguists in Europe and the cultural and linguistic capital that such scholars bring to the field is invaluable - we know of 29 deaf, signing linguists who hold a PhD in applied/theoretical linguistics across the Council of Europe territories, with clusters of more than three only in Sweden, Germany and the UK. Of these 29, one is now retired and one has left academia. To the best of our knowledge, there are no deaf PhD holders working on sign languages in over 30 Council of Europe countries (as of 5 June 2021).

The SLLS also guides sign linguists to make research results on sign languages visible in academia in general and in particular, in the specific subfields where they are directly relevant. Further, the SLLS requires that sign linguists strive to make their research results available to the broader, non-specialized audience, with the ultimate aim to generalize knowledge about sign languages and signers and to remove the traditional prejudices about them. These are core to the SignON project team's mission.

Against this backdrop, the positionality of researchers – and in particular, hearing researchers – working with Deaf communities for research purposes is something that requires our attention. Additionally, the SignON team is keen to ensure that we frame our ethical approach with due consideration to the cultures of Deaf communities we engage with over the life cycle of our project.

1.2 SignON - What Needs Ethical Approval?

For the purposes of the SignON project, any data collection that includes human subjects will be reviewed by the SignON Research Ethics Committee ahead of that proposal being submitted to the lead PI's institutional Research Ethics Committee. This includes (but is not limited to) proposed interviews with participants, focus groups, and surveys (including anonymous surveys). When re-using data previously collected, researchers should explicitly check that the specific re-use is allowed. Where the lead PI proposing a data collection process is not affiliated with a university, the application for research ethics approval will be submitted via the SignON PI to the Dublin City University REC.

Within REC applications there will be a need to clearly articulate how data will be managed to ensure that the research process will be GDPR compliant, and how sharing of personal data amongst the consortium will be addressed, if relevant. We note that there are also guidelines around data management embedded in the SignON Consortium Agreement, and a living Data Management Plan (see D7.8 and D7.10) for the project that will be co-referenced by applicants seeking ethical approval across the life of the SignON project. Researchers should be particularly careful about personal data transfer across borders, due to the different legal frameworks in each country. Guidance on this can be provided by Data Protection Officers in individual universities and by the SignON lead, DCU.

2. Guiding Principles

2.1 Research Integrity

We adopt the European Code of Conduct for Research Integrity (RI) (ALLEA (All European Academies), 2017) and will uphold the four key tenets of (i) reliability; (ii) honesty; (iii) respect and (iv) accountability in our work. We also seek to embody the eight practices that are outlined with respect to ensuring that our work meets the highest standard. These practices relate to the following:

1	Research environment	We seek to promote awareness of RI obligations across the SignON consortium and we work to ensure a prevailing culture of research integrity through our processes and practices.
2	Training, supervision and mentoring	We are committed to ensuring that all SignON researchers can access training around ethics and RI and we will offer support around particular ethical and RI considerations when working with/in Deaf communities as outlined in this document.
3	Research procedures	We are committed to carrying out our research in a careful, well-considered manner and we uphold (and seek to go beyond) the state of the art in terms of our disciplinary approaches. This applies to all stages of work from research conception, engagement with participants, through to product development and dissemination.
4	Safeguards	The SignON team complies with codes and regulations relevant to our disciplines. In particular, as a consortium we have adopted the Sign Language Communities' Terms of Reference Principles and the Sign Language and Linguistics Society's ethical guidelines outlined in section 2.
5	Data practices and management	We are committed to good data stewardship and management practices. These are outlined in section 4.
6	Collaborative working	All SignON partners take responsibility for the integrity of the research we are undertaking. We have agreed at the outset on the goals of our research and on the process for communicating our work as transparently and openly as possible. All SignON partners are properly informed and consulted about submissions for publication of the research results and we have a process in place for this, which is outlined in section 3.

7	Publication and dissemination	We have outlined our publication protocol in section 3, drawing on (and adding to) the Contributor Roles Taxonomy (CRediT). We also have a dissemination plan, which is discussed in WP6.
8	Reviewing, evaluating and editing	We follow the guidance in the European Code of Conduct for Research Integrity and take seriously our obligations around participating in refereeing, reviewing and evaluation.

2.2 Co-constructing our approach

"Deaf involvement and leadership are crucial for designing systems that are useful to users, respecting Deaf ownership of sign languages, and securing adoption." (Bragg et al. 2019, p. 23).

SignON is predicated on a co-creation model which places deaf users at the heart of our process.

We are mindful of the fact that there are exceptionally few fluent signers, hearing or deaf, working on technological projects focused on sign languages. This means that the cultural and linguistic capital that deaf communities can bring to technical projects is often absent. The SignON team is conscious that the linguistic competence required to plan, execute and deliver on such projects is often insufficient to facilitate stated project goals, which, in turn, impacts on the quality of outputs produced. We know that a common criticism of teams presenting avatar mediated machine translated content is that they don't know how linguistically limited their end product is because of this essential gap in linguistic competence.

We see this as an ethical issue and are working to mitigate this via our co-construction methodology.

We are also working to ensure that deaf community views are sought across the lifetime of the project (WP1) and that we are sensitive to cultural expectations as a consortium. We do this by having Deaf community organisations as consortium partners, informing and shaping our direction.

We also do this by ensuring that consortium members have input on issues from a Deaf community perspective. Working collaboratively in these ways we seek to find common ground between what we might consider to be deaf and hearing ontologies (i.e. different ways of conceptualising and categorising 'deafness' versus 'hearingness' – e.g. see Ladd 2003; Young, Napier, & Oram 2020).

When sign language research data or publicly broadcasted content remains under the care and responsibility of another organisation, it might be within their power to grant permission on behalf of the signers - deaf or hearing - that appear in the footage (e.g. interpreted news broadcasts). In these cases, SignON is not required to secure additional individual permission of the signers appearing in the footage. However, to build and maintain trust with the Deaf and interpreting communities, and with the goal of creating increased awareness of the project, it is in everyone's best interest that where possible, SignON also approaches these signers individually to secure their consent for re-use of data. We provide a sample template form for inviting consent for re-use of such data in Appendix 3.

2.3 Honest evaluation of what we can do in the time we have available

It is essential that we do not over-promise on what we will do within the life of the SignON project.

In our SignON D1.1 (March 2021), we outlined a range of challenges that face researchers working on sign language MT projects. These include challenges stemming from the under-documentation of sign languages, the limited number of deaf people working on MT projects, the lack of engagement with Deaf communities by many who have worked on technological driven solutions, leading to the development of products that are not fit for purpose from a Deaf community user standpoint. Sometimes the rationale behind certain tech solutions is misinformed (e.g. signing gloves are a prototypical exemplar of devices that demonstrate a lack of understanding of how signers communicate and how sign languages work (Erard, 2017; Hill, 2020)).

Further, concerns around MT tend to relate to quality. A key driver of quality relates to the fact that European sign languages are under-documented and thus SignON will have to navigate gaps in our collective knowledge around some fundamentals of linguistic description required to underpin the MT process. Additionally, as sign languages are expressed in a visual-gestural mode, we also need to better understand, describe and codify the use of gesture and depiction and examine the relationship between how and where these arise in signed versus spoken languages, their prevalence, distribution, and patterning (and see Jantunen et al. (2021) for discussion of the challenges around depiction in particular). Just this month (June 2021), the issue of the linguistic quality captured in MT was the subject of significant concern in Belgium following from the broadcast of an avatar attempting to produce LSFB (French-Belgian Sign Language) online[3]. The Wallonian Deaf community was extremely upset with the quality of content. They reported that they

[3] See: https://fb.watch/6aPZ8K23-c/ for a round table discussion between RTBF, FFSB and deaf users about this project (16 June 2021).

did not understand the avatar. One parent recorded their children watching the video and asked what they thought about the avatar. Both children replied they did not understand it and one commented on the avatar's facial expressions (which were problematic). Underpinning the quality of output was a lack of consultation with the community. The project in question is hearing-led and no engagement occurred to the best of our knowledge with the French-speaking Federation of the Deaf Belgians (FFSB). Consequently, the French Belgian Deaf community is upset and is rightly reiterating the need for researchers to adopt the "nothing about us without us" principle.

Following from this, and from our commitment to a co-construction approach, the SignON consortium are extremely mindful of the fact that we must clearly and carefully communicate our project to the Deaf communities we are engaging with. We need to be clear that there are Deaf people and organisations at the heart of this project, and we will ensure that we signpost clearly when samples we present are a work in progress. We will be extremely clear that we know that there are many things that we wish to work towards that may not be feasible given the current levels of documentation of the sign languages we are working with and/or the current knowledge around the representation of content visually/gesturally, or indeed arising from gaps in MT capacity to infer some of the pragmatic content that would underpin spatial distribution of information in signing space as a human native signer would do. These are considerations that map to our desire to be clear, transparent, respectful and engaged with the communities whom we wish to serve.

2.4. Publication protocols

A criticism of some publications that report on technological projects is the lack of inclusion of Deaf academics or consultants in projects, further compounded by the lack of grounding of many authors in the field of Deaf Studies. This often results in skewed presentation of information, including fundamental misunderstandings of how Deaf communities see themselves and their languages. This has led to significant critiques in the media as described in the SignON D1.1 and in section 1.1 above.

Our publication protocol seeks to ensure that all contributors are acknowledged. We do this by adopting the Contributors Roles Taxonomy - CRediT[4].

[4] https://casrai.org/credit/

2.4.1. SignON Adapted CRediT taxonomy

This section presents guidelines for deciding the author list of academic or non academic publications that stem from SignON. These guidelines are based on the CRediT taxonomy. We thus adopt the 14 roles defined by CRediT that describe each contributor's specific contribution to the scholarly output: 1. Conceptualization, 2. Data curation, 3. Formal Analysis, 4. Funding acquisition, 5. Investigation, 6. Methodology, 7. Project administration, 8. Resources, 9. Software, 10. Supervision, 11. Validation, 12. Visualization, 13. Writing – original draft, 14. Writing – review & editing.

The 14 roles are detailed below:

1.	Conceptualization	Proposal of fundamental ideas; formulation or evolution of overarching research goals and aims. In case the scholarly output outlines or presents all fundamental ideas embedded in the project or the project as a whole then the project main contributors should be considered to have this role.
2.	Data curation	Management activities to annotate (produce metadata), scrub data and maintain research data (including software code, where it is necessary for interpreting the data itself) for initial use and later re-use.
3.	Formal analysis	Application of statistical, mathematical, computational, or other formal techniques to analyze or synthesize data to be included in the scholarly output.
4.	Funding acquisition	Acquisition of financial support, external to the SignON project that contributes to the work described in the publication.
5.	Investigation	Conducting a research and investigation process, specifically performing the experiments, or data/evidence collection.
6.	Methodology	Development or design of methodology; creation of models.
7.	Project administration	Management and coordination responsibility for the research activity planning and execution that are specific to the publication.
8.	Resources	Provision of study materials, reagents, materials, patients, laboratory samples, animals, instrumentation, computing resources, or other analysis tools.

9.	Software	Programming, software development; designing computer programs; implementation of the computer code and supporting algorithms; testing of existing code components.
10.	Supervision	Oversight and leadership responsibility for the research activity planning and execution, including mentorship external to the core team.
11.	Validation	Verification, whether as a part of the activity or separate, of the overall replication/reproducibility of results/experiments and other research outputs.
12.	Visualization	Preparation, creation and/or presentation of the published work, specifically visualization/data presentation.
13.	Writing (original draft)	Preparation, creation and/or presentation of the published work, specifically writing the initial draft (including substantive translation).
14.	Writing (review & editing)	Preparation, creation and/or presentation of the published work by those from the original research group, specifically critical review, commentary or revision – including pre- or post-publication stages.

2.4.2. Implementation of the adapted CRediT taxonomy

Anyone who can be assigned one (or more) of the CRediT contributor roles should be considered when discussing authorship.

To decide the order of co-authors, we adopt the following approach:

- For each role, a co-author is to be assigned one of three degrees of contribution: “lead”, “equal” or “supporting” (we describe this further below). Depending on the degrees of contribution associated with each co-author, a decision on ordering of authors is to be made. The following is our recommended strategy, which can be adapted on a case-by-case basis, and with the support of all co-authors:
    - The author with the highest degree of “lead contribution” is assigned as the lead author, followed by the author with second highest degree of “lead contribution” and so on;
    - When the degree of “lead” is the same, the person with highest “equal” degree is considered next, cascading depending on contribution level;

- Where degree of contribution is the same across a number of co-authors, alphabetical order is to be assumed;
- We acknowledge that the positioning of lead-author may vary from discipline to discipline (e.g. first author may be lead author in some disciplines while last author is senior author in others).

- All co-authors should agree to the ordering of authors prior to submission.

2.4.3. Acknowledgements

The acknowledgements section should contain information about any person or entity that has contributed to the scholarly output, but does not fulfill the aforementioned criteria if that person or entity has agreed. For example, an individual who has provided minor feedback on the text; any individual who has suggested related work or provided verbal or written guidance and is not in the list of authors.

In addition, the SignON project should be acknowledged as follows:

> This work has been conducted within the SignON project. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101017255.

Any additional funding bodies should also be listed in the acknowledgements section.

3. Ethics Committee

3.1 Scope

The SignON Ethics Committee has responsibility for oversight of all research ethics applications that are submitted by consortium members. The Ethics Committee will monitor the procedures that we define through regular meetings of the SignON Research Ethics Committee (REC) (as outlined below).

We will do this by requiring any research protocol that requires ethics approval to be overseen by the SignON Ethics Committee. This allows us to ensure that the principles we uphold as a consortium are consistently implemented in our documentation.

On a practical level, this means that the SignON Ethics Committee will have sight of participant information that is shared with all stakeholder organisations who engage in our project related research activities (e.g. this allows us to confirm that Participant Information Leaflets (PILs) and Consent forms are available in accessible languages).

This is important for a number of reasons:

- Ensures access to information about the project in a language that is understandable to the participants.
- Ensures that the implications of participation are clearly articulated in an accessible language.
- Ensures that rights of withdrawal without consequence are clearly articulated in an accessible language.

We note that only adults who are able to give informed consent will be invited to participate in this project - we are not targeting children or vulnerable populations in this process.

The SignON REC will track for potential gendered/generational views to the technologies in development as this will inform our socio-cultural response to co-creation of the SignON content. Participants will be notified of this in data collection processes as relevant (e.g. focus groups). To achieve this, this task will use the DMP (D7.8) as a basis for support.

The SignON REC will evaluate how privacy, ethics, legal and societal impact requirements are approached, and monitor to ensure that are in accordance with this policy.

The SignON REC requires that each WP leader advises the REC of the data collection planned for their work package. This helps ensure that the SignON REC has oversight of the work planned in this regard, and can advise on ethical matters as needed.

The SignOn REC will ensure that protocols written into local research ethics permission applications are aligned to our co-creation approach and are observant of best practices as laid down in the European Code of Conduct for Research Integrity (ALLEA (All European Academies), 2017) and in Deaf studies aligned approaches.

Finally, the SignON REC will review partner specific Data Management Plans (DMPs) as outlined in D7.8 and further mentioned in section 4 below.

3.2 Membership

	Name	Institution	Country
1	Prof Lorraine Leeson	TCD	IE
2	Dr Dimitar Shterionov	TiU	NL
3	Dr Vincent Vandeghinste	INT	NL
4	Dr Henk van den Heuvel	RU	NL
5	Prof Josep Blat	UPF	ES
6	Jorn Rijkaert	VGTC	BE
7	Prof Dr Myriam Vermeerbergen	KUL	BE
8	Dr Catia Cucchiarini	DLU	NL
9	Aoife Brady	DCU	IE

3.3 Meeting Schedule

The SignON Ethics Committee will meet monthly from March to June 2021, then every two months, or as needed to respond to a consortium partner local REC deadline.

2021	March, April, May, June, September, November
2022	January, March, May, July, September, November
2023	January, March, May, July, September, November

We will also report back to the Work Package Leads Meeting on a monthly basis.

3.4 Complaints/Appeals

Any complaints or appeals will be reviewed by the Project Management Board (PMB) in line with the processes described in the Consortium Agreement.

3.5 SignON REC Folder and Email List

An ethics folder for the SignON REC has been set up containing all WP9 related documentation. It is at: https://drive.google.com/drive/u/1/folders/1CH38L52A_oxOc2IaIhmvUUvmgM_AeypQ

An email address for the SignON REC has been established: signon-rec@adaptcentre.ie.

3.6 Consortium Partner Obligations

Consortium partners leading individual ethics processes are required to do the following:

- Prepare ethics applications for their local Research Ethics Committee, in line with guidance available from those sources;
- If a partner is not affiliated to a university, they should consult with the Lead Partner and prepare a REC application for submission to Dublin City University (DCU);
- Ensure that principles that we outline here for working with deaf communities are folded into the application processes and procedures;
- Bring the draft REC application to the SignON REC for oversight and guidance ahead of submitting to an institutional REC. This should be sent to signon-rec@adaptcentre.ie
- Present the proposal to the SignON REC meeting;
- Maintain templates of informed consent forms and information sheets on file;
- Maintain copies of approvals by ethics committees for all research including humans, and signed copies of consent forms for as long as has been advised by the Data Protection Officer [in line with GDPR];
- Submit a copy of the final approved REC application and notification of approval from the local REC committee for the study;
- Submit a copy of the final approved Data Management Plan (if relevant). This will be included in D7.10;
- Log any issues that may arise from an ethical or data management perspective to the SignON REC and their local REC or designated Data Protection Officer;
- Log any change of protocol notifications to the SignON REC and their local REC.

4. Data Management

While our project will focus quite intently on pre-existing data sets such as digital sign language corpora and publicly available content (with appropriate direct and indirect permissions as

necessary), we have also given due consideration to how we will handle and curate new data over the life of SignON and beyond.

Where possible, project members will reuse existing data, either public, or from project partners or related institutions. Pre-existing datasets held by SignON project partners are shared under the terms of the SignON Consortium Agreement, which all partners have signed up to. External pre-existing data sets will be obtained from public broadcasters, government information services, CLARIN data centers[5], and established data warehouses such as LDC[6], ELRA[7]. In all cases, appropriate consents/data reuse agreements will be confirmed.

New data that will be collected will require a two-stage process of ethics clearance. That is, when we seek to collect data (e.g. from participants in focus groups, or in creating additional data sets to supplement existing corpora), partners will prepare an ethics application for their home institution, or, if they are a non-university partner, an application for research ethics approval will be submitted via the coordinating partner institution, Dublin City University. Before submitting their application to their institutional research ethics committee, the application will be reviewed by the SignON REC, which will ensure that these key principles are embedded in our research processes and practices:

- All SignON researchers will be required to confirm that they have received training regarding their obligations around GDPR.
- Collection of personal data will be minimised insofar as possible.
- Informed consent will be secured from participants in all SignON data collection processes.
- All participants in any data collection process will have access to information in plain language and/or a signed language, as is their preference.
- Information that is video recorded will be used only for the purposes that are advised, and kept only as long as necessary (e.g. focus group data that is video recorded will be later transcribed and pseudo-anonymised). However, we note that some data collection may enrich existing corpora and should, assuming appropriate permissions from participants are in place, be curated as FAIR materials.
- Primary responsibility for observing good practice in the use, storage, retention and preservation of data sits with the individual SignON researcher, supported by the SignON consortium.

[5] https://www.clarin.eu/content/overview-clarin-centres
[6] https://www.ldc.upenn.edu/
[7] http://www.elra.info/en/

- Any research data that the SignON consortium collects will be recorded in a clear and accurate format. Particular attention will be paid to the completeness, integrity and security of our records.
- Any research data we collect will be stored in secure and accessible form and will be retained for a length of time in accordance with institutional, funder and/or publisher requirements (also considering FAIR usage). This information will be listed in documentation shared with participants engaging in data collection processes across the life of the SignON project.
- SignON researchers will publish results and interpretations of our research in an open, honest, transparent and accurate manner, and respect confidentiality of data or findings when legitimately required to do so. We also note that given the nature of sign language materials, the image of the participant is an essential vehicle of the linguistic message. In this, we will explore whether participants who consent to their images being used in publications/presentations/subsequent teaching and learning contexts wish to be assigned pseudonyms or if they wish to be acknowledged and named, something that many deaf participants have requested in our experience (e.g. see Leeson and Saeed's (2012) foreword acknowledging and naming (with permission) the contributors to the ISL corpus).
- SignON has created a deliverable D7.8 which contains the framework and requirements for the Data Management Plans of each project partner. D7.8 is complemented by the specific DMPs for each partner. These will be included in D7.10 which is due M36. In order to accommodate the dynamic nature of DMPs, intermediate versions of D7.10 are scheduled for M12 and M24. These specific DMPs will be reviewed by SignON's REC.

The consortium takes the position that special data protection provisions above those required for personal data are not needed. DHH adults are not inherently vulnerable. In SignON, we are engaging with DHH adults with the capacity to give informed consent in a language that they understand to participate in the project's activities. We are not targeting participants who are under 18 years of age. We are not specifically targeting any DHH participants who are vulnerable (e.g. DHH participants with an intellectual disability). We are not collecting any metadata that relates to the health of any individual - our focus is solely on participants' linguistic backgrounds and their experiences with and attitudes to MT.

5. Conclusions

This report has presented an overview of key challenges that have been documented in the field of machine translation and other technological responses to communities using sign language. In response to these challenges, SignON is committed to a number of principles that reflect state of the art thinking on how to ensure that machine translation projects best serve Deaf communities:

- SignON is committed to co-creation, evidenced by the leadership of deaf researchers and deaf community organisations as central to the SignON work, and, through our partners, recursive rounds of engagement with deaf signers from across our target language communities.

- SignON is committed to ethical approaches in our engagement with deaf and hard of hearing communities, with regard to data collection, management, and curation, and in our representation of our research findings.

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APPENDIX 1: Sample SignON Participant Information Leaflet

[SAMPLE] PARTICIPANT INFORMATION LEAFLET

For Participants in

The SignON focus groups

INFORMATION SHEET

You have been invited to participate in the SignON focus group.

We, NAME, NAME, and NAME, are INSTITUTION'S researchers in charge of organising the focus groups. In order for you to take an informed decision as to whether to take part or not, it is important that you understand:

(a) What the Action is about;

(b) Why the Action is important;

(c) What your participation in the focus group, organised by EUD, would involve.

This Information Sheet is designed to explain these aspects to you. If needed, we are available to give you further information**.**

1. DESCRIPTION OF THE PROJECT AND THE FOCUS GROUP

This project will research and develop the SignON communication service that uses machine translation to translate between Sign and spoken languages. This service will facilitate the exchange of information among deaf and hard of hearing, and hearing individuals. In this user-centric and community-driven project we will tightly collaborate with European deaf and hard of hearing communities to (re)define use-cases, co-design and co-develop the SignON service and application, assess the quality and validate their acceptance. Our ultimate objective is the fair, unbiased and inclusive spread of information and digital content in European society. Our project will develop a free, open application and framework for conversion between video (capturing and understanding Sign language), audio and text and translation between Sign and spoken languages. To ensure wide uptake, improved sign language detection and synthesis, as well as multilingual speech processing on mobile devices for everyone, we will deploy the SignON service as a smart phone application running on standard modern devices. The project will be driven by a focused set of use-cases tailored towards the deaf communities. We target the Irish, British, Dutch, Flemish and Spanish Sign and English, Irish, Dutch, Spanish spoken languages. However, SignON will incorporate sophisticated machine learning capabilities that will allow (i) learning new Sign, written and spoken languages; (ii) style-, domain- and user-adaptation and (iii) automatic error correction, based on user feedback.

The actual focus group will, through a grid of questions, contribute to understanding user needs and practices and discuss how the SignON mobile app could be used in everyday life.

2. WHAT ARE THE POSSIBLE BENEFITS AND DISADVANTAGES OF TAKING PART IN THE FOCUS GROUP?

Taking part in the focus group, you will not be placed in any situation in which there is a likelihood of physical, mental or emotional harm. Furthermore, you will not be placed in any environment threatening to your physical or mental integrity. Potential cultural hurdles were identified in advance and *ad hoc* measures were taken in order to avoid any incident. We, [INSERT NAMES OF PIs] , are available to satisfy any reasonable request or need you might have.

If you have been invited to this focus group by your employer, be assured that you are under no undue explicit or implicit pressure to take part. Taking part entails no advantage in terms of your employment and not taking part implies no disadvantage. Disadvantages related to taking part to the focus group include potential loss of time and the cost of attending/conducting the activity, which is not paid nor reimbursed.

You will not be provided any incentive to take part in the focus group.

Although your participation is genuinely aimed at getting your opinion, feedback and/or comments on a specific topic in the focus group, there could be a risk that you may share some confidential information by chance, or that you may feel uncomfortable talking about some issues. However, we do not wish for this to happen. You do not have to answer any question or take part in the discussion if you feel the question(s)/topic is (are) too personal, or if talking about them makes you uncomfortable. If you say anything of which you afterwards realise you do not want it to be reported or anyhow used for project research purposes, you can inform us at any given moment during your participation in the focus group, or when it is over.

You have – and understand that you retain it at all times – the right to withdraw yourself and your data from the focus group and, in general, from the study . You may do so for any (or no) reason and without prejudice. You may be asked for a reason, but be clear that there is no obligation, and that you are under no pressure whatsoever, to answer. You will be briefed, from the outset, on the procedures for ending your participation to the focus group, i.e. by simply expressing your free choice to withdraw.

3. CONFIDENTIALITY

A data minimisation policy is adopted by [INSTITUTION/ORGANISATION], so that no data that is not strictly necessary for the focus group is collected and processed.

By taking part in the focus group, you will be asked to provide the following information:

Your full name, gender (M/F/X), date of birth, nationality, and country of residence.

Your personal data will be collected and processed by [INSTITUTION/ORGANISATION]s research team in charge of organising and following-up the focus group. In particular, they will be processed by [RESEARCHERS NAMES], for the purpose of the focus group and carrying out project research activities only.

The data you provide by compiling and signing this Informed Consent will be gathered on computer files, and accessed only by us or other selected [INSTITUTION/ORGANISATION] personnel who might be authorised to work on the project. Unauthorised access is prevented by the adoption of the following security measures: we will employ a password to get access to computer files storing your personal data; your data on this computer is encrypted through available encryption software.

These data will not be shared in any case with, or disclosed to, anyone outside the [INSTITUTION/ORGANISATION] research team (to other project partners neither). If needed or required, they might be shared with the EU Commission. However, we may disclose collected personal information to the extent that it is required to do so by law, in connection with any legal proceedings or prospective legal proceedings, and in order to establish, exercise or defend our rights.

As already stated, by taking part in the research, you will be asked to provide your personal or professional views or opinions on the user needs and practices to be addressed in the project. These data will be gathered through a focus group approach, which means that information will be exchanged through Sign Language, and that the session will be recorded. Any personal or professional views or opinions you might express during the focus group will be anonymous or anyway rendered anonymous before dissemination. This implies that by no means the opinions or views you expressed will be related to your personal data. In other words, your opinions or views will be processed in a way that inhibits tracing them back to you.

All personal data collected and stored within the scope of the project and for the purpose of the project will be permanently and irrevocably erased upon the completion of the project (31/12/2023).

4. CONSIDERATIONS REGARDING ONLINE PARTICIPATION

For the following reasons this research will be conducted online via zoom:

- Health considerations: due to the COVID pandemic we will conduct the research online in order to ensure there are no risks to interviewees (participants) nor interviewers (SignON researchers).
- Traveling considerations: we will conduct this research online in order to avoid travelling to different locations, thus save time and resources in organizing and conducting the interviews.

Zoom (zoom.us) will facilitate the remote conversations as well as, recording of audio and video. The following protocol will be used:

- Any participant (interviewer or interviewee) will need to update their zoom to a version no earlier than 5.52 to ensure all conversations are encrypted (using end-to-end (E2E) encryption).
- Participants will be sent a link to a password-protected zoom meeting; the meeting will be from a secure, DCU zoom account.
- The DCU zoom account ensures that camera tracking is not allowed.
- Interviewees will not be able to join the zoom meeting without the host (i.e. the interviewer)
- Upon accessing the zoom meeting link, interviewees will await admittance to the meeting by the host (one of the interviewers, a SignON researcher). That is, zoom will have ‘waiting room’ enabled.
- To avoid ZoomBombing -- when one of the people in a meeting shares their screen without the host’s permission and may take that opportunity to share content that the host does not wish any of the participants to see -- screen sharing will be disabled by default. Only after request during the meeting, the host may allow screen sharing for interviewees.
- To avoid bullying, direct chat between participants will be disabled; only chat in the common chat space will be allowed where the interviewer can view all exchanged communication.
- The interviewer may create breakout rooms -- subchannels to the main meeting where only a part of the interviewees’ group can participate -- and group interviewees in smaller groups to discuss a certain topic in these breakout rooms.
- In case of any undesired behaviour by individual interviewees towards the other participants, the host (i.e. the interviewer) has the right to remove them from the meeting.
- Zoom meetings will be recorded (audio and video). The recordings will be kept until 6 months after the end of the project. After that they will be permanently deleted. The recordings will be viewed by SignON researchers as well as by professional interpreters to facilitate the translation and transcription of the videos.
- Interviewees can withdraw from this research if they do not wish to participate in the Zoom interview.
- Upon completing the interviews, interviewees will have the right to access personal data relating to them, and the right to object to the processing of personal data relating to them.

5. IF YOU WOULD LIKE TO TAKE PART IN THE FOCUS GROUP

Please understand that participation is entirely voluntary: you are under no obligation whatsoever to take part in this survey. No disadvantage or stigma will arise should you decide not to participate.

6. FURTHER INFORMATION

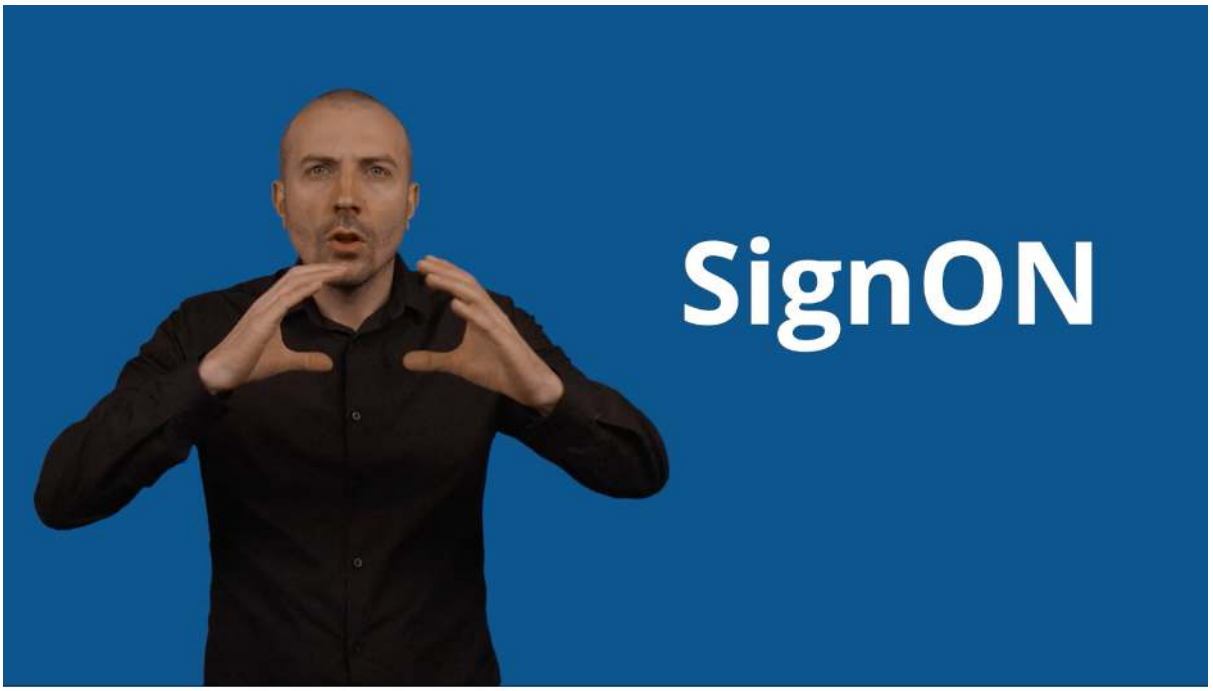
Thank you for taking the time to read this Information Sheet. If you have any questions about any aspect of the focus group, or your prospective involvement in it, please contact:

NAME
Email: EMAIL ADDRESS
Address: ADDRESS

APPENDIX 2: Sample SignON Consent Forms in International Sign and English prepared by EUD

An **International Sign** version of the consent form can be viewed here:

https://vimeo.com/527721644/5ae48d77d6



SIGNON.mp4

ENGLISH version sample:

SignON Project: facilitating the exchange of information among deaf, hard of hearing, and hearing individuals across Europe

CONSENT FORM

(Principal Investigator) - [email address]

[Researcher 2 - email address]

[Researcher 3 - email address]...

Research Study Title

I confirm that I have been invited to participate in the SignON project which is funded by the European Commission. The principal investigator for [INSTITUTION] is [LEAD RESEARCHER NAME]. Other team members are [LIST THEM HERE]. I understand that other people within the SignON consortium might work with the [INSTITUTION/DEPARTMENT] team to write up project findings.

Clarification of the purpose of the research

I know that I am going to be interviewed about the topic of machine translation for [X] Sign Language. I confirm that I know that the Data Controller is [INSTITUTION].

Confirmation of particular requirements as highlighted in the Plain Language Statement

Participant – please complete the following (Circle Yes or No for each question)

- I have read the Participant Information Leaflet (or had it read to me or seen it in XSL).

YES **NO**

- I understand the information provided.

YES **NO**

- I have had an opportunity to ask questions and discuss this study.

YES **NO**

- I have received satisfactory answers to all my questions.

YES **NO**

- I am aware that my interview will be recorded.

YES **NO**

- I know I can withdraw from the research study at any point.

YES **NO**

- I know my contact details will be used to help schedule interviews but will not be shared outside the research team.

YES **NO**

- I know my name will be removed from my interview and that the research team will take any identifying information out of their research report.

YES **NO**

- I understand that because the Deaf Community is small, the research team cannot absolutely guarantee that others reading the report who know me won't recognise the things I've said.

YES **NO**

- I know my interview video recording and my contact details will be kept for seven years after the SignON research project finishes and will be deleted after that by [NAME PARTY RESPONSIBLE].

YES **NO**

- I know my typed, anonymized, interview transcript (without my name) will be kept indefinitely.

YES **NO**

- I know that the confidentiality of information provided is subject to legal limitations.

YES **NO**

Signature:

I have read (or had read or signed in [X] SL to me) and understand the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of the Participant Information Leaflet that relates to this study. Therefore, I consent to take part in this research project:

Participant's Signature:

_____

Name in Block Capitals:

_____

Date: _____

Researcher's Signature:

_____

Name in Block Capitals:

_____

Date: _____

APPENDIX 3: Sample SignON Consent Form for Reuse of Data

Informed Consent

Title of the study:
SignON: Sign Language Translation Mobile Application and Open Communications Framework

Name + contact details of project managers:
[INSERT HERE]

Aim and methodology of the research:
The research aims to develop machine translation technology between sign languages and spoken languages. Large amounts of training material are required to achieve this. This training material consists of videos in which the spoken content is translated or interpreted by translators or sign language interpreters. By transcribing the spoken content via autocues, subtitles or automatic speech recognition, a parallel corpus is created with on one hand the video of the sign language (who signs for example in Irish Sign Language) and on the other hand a written record of what is being said, in a spoken language (for example English). Based on this material, we want to research (1) automatic sign language recognition, (2) automatic translation from a sign language to a spoken language, (3) automatic translation from a spoken language to a sign language, (4) automatic synthesis of sign language through a virtual sign language signer and (5) a better linguistic understanding of sign language.

Funding of the project:
The SignON project is funded by the European Commission. Grant Agreement number: 101017255 - SignON - H2020-ICT-2018-20 / H2020-ICT-2020-2

Use within the SignON research project

☐ I consent to the researchers to use videos with myself as a sign language interpreter or translator for research in the SignON research project

yes no

I confirm that I consent to the researchers of the SignON project contacting me again with any follow-up questions

yes no

Availability for further research targeting the above-mentioned research goals

I consent to making the video files available for further scientific research for the aforementioned research objectives. Only those who are affiliated with a research institution can use the corpus[8].

[8] Any research institution with the same goals would then be given permission to access the data. These goals are working on: (1) automatic sign language recognition, (2) automatic translation from a sign language to a spoken language, (3) automatic translation from a spoken language to a sign language, (4) automatic synthesis

yes no

I give permission for my data to be pseudonymised and for data relating to the transcribed recordings that I appear in to be made available for the above-mentioned research. Only those who are affiliated with a research institution can use the corpus.

yes no

I confirm permission for the video footage with transcriptions to be made available after the project, through the [INSERT INSTITUTION'S NAME]. Only those who are affiliated with a research institution can use the corpus. The CLARIN infrastructure (https://www.clarin.eu/) is used for this.

yes no

Results

I confirm that the results of this research can be used for scientific purposes and may be published. My name or other personal information will not be published. The confidentiality of the data is guaranteed at every stage of the research.

yes no

Participation

☐ I understand that my participation in this study is voluntary. I understand that I can withdraw my participation at any time without any repercussions.

yes no

Myself or others may benefit from this research in the following ways:
Communication between deaf and hearing people may improve as a result of access to the SignON application. Knowledge about the linguistic characteristics of sign languages may increase, leading to increased general acceptance of sign languages as natural languages.

I would like to be kept informed of the results of this research. The SignON researchers may contact me for this at the following e-mail address: _____

- For questions as well as for the exercise of my rights (access to data, correction thereof, ...) I know that when participating I can contact:
[INSERT CONTACT PERSON AND CONTACT DETAILS HERE].

of sign language through a virtual sign language signer and (5) a better linguistic understanding of sign language.

I have read and understood the above information and have received answers to all my questions regarding this study. I agree to participate.

Date:
Name and signature of participant. Name and signature of researcher.