The Social Inclusion and Community Activation Programme (SICAP) aims to improve the life chances and opportunities of those who are marginalised in society, living in poverty or in unemployment, through community development approaches and targeted supports. Without accurate data it is impossible for SICAP to monitor and assess the effectiveness of the SICAP programme.

**Ethnic data is needed to:**

- Promote equality;
- Combat racism and discrimination;
- Monitor progress of programmes and policies;
- Inform evidence-based policymaking;
- Identify barriers and issues for various groups in accessing and using services;
- Plan and deliver culturally inclusive services; and
- Feed information back to service users.
Introduction

In 2015 the Social Inclusion and Community Activation Programme (SICAP) introduced an ethnic/cultural background question into the programme monitoring system (IRIS). A number of regional training events and a national seminar were held in the same year to familiarise frontline staff with the new equality question. Feedback from these sessions indicated a need for further training and materials to support staff. These guidelines are a practical tool to support SICAP staff and embed an understanding of human rights compliant approaches to ethnic equality monitoring.

The guidelines have been prepared taking into account the challenges that staff face in gathering personal data such as ethnicity/cultural background. These can include low response rates from service users, lack of understanding of the rationale for the question and fear of discrimination following disclosure. These guidelines are not intended to provide all-encompassing protocols but rather, to offer a clear rationale for the collection of ethnic data, an overview of good practice and a broad understanding of how intercultural approaches can inform equality monitoring. Key components of this approach include: human rights, equality, anti-discrimination, participation and empowerment, all of which underpin the Ten Common Basic Principles on Traveller and Roma Inclusion.

SICAP targets the most disadvantaged groups in Ireland. However, how can this be assessed if outcomes for specific target groups are not measured? Collecting accurate information about which groups are using (or not using) SICAP supports is a good place to start.

Why collect ethnic data?

Since the early 1990s civil society groups, human rights bodies, minority ethnic groups, and in particular, Traveller organisations have called on Irish public bodies to implement an ethnic identifier in their datasets, within a human rights framework. This means there must be a universal question, which is answered voluntarily based on self-identification and data is anonymised to avoid identification of specific individuals. In summary, accurate data is required to:

- Inform evidence-based policy and service planning;
- Identify discrimination and promote equality;
- Challenge discrimination; and
- Promote equality and inclusion.

Without data, it is impossible to highlight the existence of systemic or indirect discrimination and inform good policy and practice. Groups welcomed SICAP’s inclusion of an ethnic identifier into the IRIS system for the first time in 2015, as it can ensure that:

- Specific target groups are not being excluded;
- Individuals are registered in the most appropriate categories; and
- Interventions and services can be tailored to specific needs.
This data has already yielded valuable information for both key stakeholders and SICAP as they can deliver a more equal and responsive service locally by tracking and responding to emerging trends. At national level, it shows where SICAP is targeting the most marginalised, while at the same time, it identifies gaps where engagement is lacking and/or can be improved. Analysis of this data also shows the extent to which each programme implementer (PI) engages with people from ethnic and cultural minorities, and PIs can draw on the data on a city/county level to build greater engagement with target group representatives. This helps PIs ensure that their statutory obligations as public bodies are met as per Section 42 of the Irish Human Rights and Equality Act (2014). Furthermore, the person seeking a service can be provided with appropriate supports or referrals for example, literacy, translation, technical skills training, etc.

Challenges in ethnic data collection

Many PIs feel ill-equipped to ask questions about sensitive or personal information. They may feel that asking questions about ethnicity can offend or create a barrier in establishing trust with the individual. There is also unease that asking the question might seem discriminatory and could result in service users disengaging from programme supports. However, ethnic data can be collected with the right approach and this needs to be planned for and incorporated into equality training and support for staff. This includes the way the question is asked, making sure that individuals clearly understand the reasons for collecting data, and how the data will be used to promote equality. Reluctance to reveal ethnic identity is directly connected to lack of trust often based on previous negative experiences of discrimination or perceptions that the data will be used negatively. This is especially true for minority ethnic groups such as Roma, Travellers and other groups who may have experienced data abuse in the form of ethnic profiling, segregation, forced sterilization and in some cases, violence and genocide.

PIs must provide clear guidance on why the data is being collected, who will have access to data, how it will/will not be used and how the data can benefit the service user. It is important that individuals are reassured that all information is completely confidential, anonymous and will only be used to inform SICAP so that the programme can better meet individuals’ needs and promote equality.
1. What is ethnicity?

Everyone has an ethnicity and people can belong to more than one ethnic group. An ethnic group is made up of people who share some or all of the following:

- Shared history
- Common cultural tradition
- Common geographical origin
- Descent from common ancestors
- Common language
- Common religion
- Distinct group within a larger community

Ethnicity is recognised as one of the nine grounds on which discrimination is prohibited under equality legislation in Ireland. Ethnicity should not be confused with nationality or citizenship.

2. Nationality

Nationality is a category used in the IRIS system and we refer to it here in order to distinguish it from ethnicity. It is acknowledged that nationality is a contested concept that can refer to country of birth but is often used to mean citizenship, for example, the CSO ask three separate questions in the Census – place of birth, nationality (which in this instance means citizenship) and ethnicity.

In Ireland and some other countries, ‘nationality’ is often used interchangeably with ‘citizenship’ and ethnic groups can have different nationalities, for example, Travellers can be Irish, British, Dutch or any other nationality. Similarly, Roma can be Romanian, Czech, Slovakian, etc. It is important that PIs do not assume they know the nationality of service users based on their ethnic/cultural background or vice versa as this could lead to misclassification and could affect the supports offered to service users, for example in relation to interpreter services.

3. Citizenship

This information is not collected in IRIS and PIs are not required to ask. However, for information purposes, citizenship is a legal status, which means that a person is legally recognised by a country through birth, naturalization, descent, declaration, marriage or other means. Irish citizens are entitled to hold an Irish passport, stand for election in Ireland and the EU and travel/work within the EU/EEA. A person can change their citizenship and in some cases, hold dual citizenship.
4. What does the law say about collecting ethnic data?

Collecting ethnic data is legal under both Irish\(^4\) and European\(^5\) data protection law and encouraged by international human rights monitoring mechanisms once data is:

- Aggregated and anonymised to avoid identifying specific individuals;
- Collected fairly (both through voluntary self-declaration and explicit consent) and for specified legitimate purposes; and
- Accurate and adequate, relevant and not excessive to the purpose for which it is stored.

Other public bodies in Ireland collecting, monitoring and using ethnic data include but are not limited to:

- Central Statistics Office (CSO)
- Primary and secondary schools
- Universities and the Higher Education Authority (HEA)
- Hospitals (including maternity units, children’s hospitals and psychiatric units)
- National Drug Treatment Reporting System (NDTRS)
- Irish Prison Service (IPS)
- Health Protection Surveillance Centre (HPSC)
- Child and Adolescent Mental Health Service (CAMHS)
- Cystic Fibrosis Registry of Ireland

5. Are PIs required to ask this question?

Yes. PIs are required to ask each service user this question but a person has a right to decide whether or not to answer it.

However, PIs should stress that the information will be used for equality purposes only and will help to prevent discrimination. For example, the SICAP (2016) mid-year review data reflected a disproportionately low level of activity with Travellers, Roma and people with disabilities. As a result the Department responded to this by issuing a communication to all LCDCs and PIs urging them to strengthen engagement with these groups in both current and future planned activities for 2016 and in 2017.

Further, Section 42 of the Irish Human Rights and Equality Act (2014) gives public services funded by government, including SICAP, a general duty to:

- Eliminate discrimination;
- Promote equality of opportunity;\(^6\) and
- Protect the human rights of its service users and staff.

Accurate and anonymised information on the composition of service users is essential to complying with this positive duty requirement and demonstrating that general duties to eliminate discrimination and promote equality are being met by PIs. Failure to monitor the provision of supports to target groups such as ‘new communities’ or minority ethnic groups (including Travellers and Roma) may constitute non-performance of the positive legal duty on public bodies. Broader training and organisational buy-in will also be necessary to comply with legislation.
6. How can ethnic data inform my work on a day-to-day basis?

To understand the needs of service users and to develop actions to tackle the barriers and issues faced by groups, SICAP collects a range of information including the ethnic/cultural background of service users.

Collected data can be used to inform and support work to realise rights of minority ethnic groups. Without data, minority ethnic groups remain uncounted and invisible. Social inclusion programmes can assist in bridging this gap and use data to inform efforts to build greater engagement with minority ethnic groups at local level. PIs should make it clear to people seeking SICAP supports that this question is being asked of all service users to determine how the programme can best help them.

Using ethnic data to target services

The National Drug Treatment Reporting System (NDTRS) has acknowledged the value of collecting ethnic data in routine assessments. Prior to the implementation of an ethnic identifier in its datasets in 2007, the NDTRS relied on anecdotal information from service providers that Traveller men were a high-risk group for opiate use and risky injection behaviours. However, using the ethnic data collected from service users, the NDTRS found that, in fact, Traveller women reported higher rates than Traveller men which should help the NDTRS to deliver more targeted interventions.

Using ethnic data to improve healthcare in Ireland

The collection and use of ethnic data in health settings has been recognised globally as key to good service provision and health equity. Maternity units, in particular, require this information to ensure that care is tailored to specific cultural/ethnic needs and additional genetic screenings are offered. For instance, in Ireland, Classical Galactosaemia is particularly common among infants born to Traveller parents. The disorder may be life threatening if not detected and treated during infancy.

To prevent this, all infants born to Traveller parents are screened at birth and are placed on glucose free milk until the result of the test is available. This would not be possible without the efforts of Traveller organisations to promote voluntary self-identification amongst Traveller women and indeed the collection of such data by maternity units. While ethnic data in this context is imperative for clinical purposes, it also allows hospitals to deliver targeted services that are culturally sensitive.
7. Is it difficult to collect ethnic data?

There are a number of barriers to collecting ethnic data including a lack of understanding about why ethnic data is collected and many are concerned about offending people. These challenges are real, but not insurmountable. There are several steps, which can be taken to encourage higher response rates. Best practice in this area stresses the importance of:

- A universal question within a human rights framework (i.e.) everyone is asked to identify the ethnic group to which they belong, not just minorities.
- Ensuring that service users are provided with a clear explanation about why the data is being collected, how it will be stored and used to promote equality;
- Practical tools such as providing a card listing the ethnic categories on the IRIS form to individuals before asking them to answer.

8. What if service users do not want to disclose their ethnicity?

Not all service users will want to disclose their ethnicity. There are several barriers that may discourage a service user from disclosing their ethnicity to the PI. These include:

- Lack of trust and rapport with the PI or other ‘official’ bodies.
- Fear of adverse treatment or discrimination.
- Fear that data will be shared with other government departments and 3rd parties.
- They may have been treated negatively in the past following voluntary self-disclosure to the extent that it may pose a threat to their personal/family safety.
- They may come from a country where ethnic data is not collected or data collectors can ascribe ethnicity based on objective criteria. For example, skin colour, clothing, address, surname, place of birth, etc.

PIs can encourage voluntary self-identification reassuring that personal data will not be used to discriminate against service users, their data will be confidential and under no circumstances will individuals be identified.

Please note: Service users ultimately have the right to decide to answer this question and PIs will not record this information unless they are given consent. However, there is a requirement on PIs to ask the question and to stress that disclosing this information will help promote equality and ensure that programmes continue to be resourced.
9. I feel uncomfortable asking this question; I am afraid that I might offend or create a barrier in establishing trust with the service user.

PIs play a key role in ensuring that collected data is accurate and if there is unease in asking the ethnic/cultural background question, service users will be equally reluctant to answer. It is important that PIs fully understand why the question is being asked and can provide comprehensive answers to any questions that service users may have, for example, why am I being asked this question? When PIs understand why these data are collected and why individuals need to self-report this information, staff discomfort is minimized. Again, the rationale for this question is to better meet individuals’ needs and ensure that direct or indirect discrimination is identified and addressed.

8. These guidelines can assist with other sensitive questions in the SICAP registration form such as the question about discrimination. Further guidance on completing the registration template can be found here: https://www.pobal.ie/FundingProgrammes/SocialInclusionandCommunityActivationProgramme(SICAP)/Documents/SICAPTrainingGuideIndRegistFormV12Clean.pdf

10. When is the best time to ask this question?

PIs have indicated that it is better to ask sensitive questions once trust has been established and good practice models support this approach. However, if this is not possible and there is insufficient time to establish rapport with the service users, staff should clearly outline the rationale for the ethnicity question which is to promote equality and eliminate discrimination. Again, confidentiality and anonymity of answers should be assured.

Suggested approaches to use:

“We want to make sure people using our services receive the most suitable support possible. With this in mind, we would like to collect information about your ethnic/cultural background so that we can make sure everyone is treated equally. I can assure you that this information will be anonymous so that you will not be identified.”

“The information is private and will not be shared with any government department. It will only be used to offer you the best supports we can and to prevent discrimination. Also, if we don’t target our services properly the government will not give us the funds to deliver these services.”
11. Who decides the ethnicity of the service user?

The service user must self-select and report their ethnicity. It is important that individuals are provided with all available categories to ensure an informed selection. If respondents are not provided with all available responses it could lead to misclassification and inaccurate data. For example, some Travellers may respond ‘Irish’ when asked for their ethnic/cultural background because they are unaware that ‘Irish Traveller’ is an option. Equally, Roma might respond ‘Romanian’ or ‘Czech’ if not provided with a list of ethnic categories.

Taking into consideration the diverse needs of service users, including individuals with limited English and/or literacy difficulties, PIs should read out all options (including both main and sub-categories) before the respondent gives an answer. A card with a list of the categories is also effective as service users can look through the options and self-identify.

12. If I know a service user is from a minority ethnic group but does not identify can I answer the question for them?

No. Individuals must identify their own ethnicity and PIs cannot guess ethnicity or complete the question on behalf of the service user based on what they perceive to be the person’s physical appearance. This is a breach of human rights standards and data protection law; it can also result in misclassification. It is important that individuals are given the opportunity to voluntarily self-identify and provide explicit consent to the processing of their personal data on the consent form which will have been provided at registration. Consent for sensitive questions can be added at a later stage in the interview.

Even in cases where PIs are confident that they know a service user’s ethnicity they cannot assign an ethnicity. The only person that can identify an individual’s ethnicity is the individual.

While service users may be reluctant to self-identify during initial contact, PIs should provide the opportunity for service users to re-identify/amend their ethnic category in subsequent meetings.
13. What should I do if I believe that a service user is of a different ethnicity than he/she claims to be?

PIs must accept the answer given and record it on the IRIS system.

14. What if a service user asks for my opinion on how they should answer?

PIs must explain that they cannot decide for the individual; individuals must decide their own ethnic/cultural background. PIs should read out all options provided before the respondent gives an answer. Again, a card with a list of the categories can be effective as service users can look through the options and voluntarily self-identify. The scenarios at the end of this document have been designed to assist PIs in understanding the real fears and beliefs amongst minority ethnic groups including Travellers and Roma, as they may have been treated negatively in the past after disclosing their ethnicity.

15. Why aren’t all ethnic categories included in the IRIS form?

The category ‘Other, including mixed background’ can be used for individuals who feel their ethnic/background is not reflected in the available categories.

The categories used in IRIS follow standard classifications developed by the Central Statistics Office (CSO) for the national census, with the additional category of Roma. This is to ensure consistency and comparability with census data. Evidence shows that people are more willing to answer questions about their ethnic/ cultural background so long as the questions are acceptable. The ethnic/cultural background question was widely tested before it was used in Census 2006 and achieved a high response rate in 2006 and 2011.

[Note: It is acknowledged that a range of ethnic groups are not represented in the national census or IRIS system. However, in preparation for the next census, the CSO will review all categories. This is in line with best international practice as categories should be updated regularly in accordance with the composition of the population in addition to principles that allow multiple ethnic classifications.]
16. The question is restrictive as it only allows one option to be ticked. What if someone identifies with multiple ethnic groups?

PIs should advise that they can select ‘Other, including mixed background’ option and write in the group(s) they identify with. This can also be used for people whose cultural/ethnic background is not listed. (See scenarios 2 & 5 for further information)

17. Time is quite limited with each individual. How much extra time does collecting ethnic data add to the registration process?

The ethnic identifier does not add significantly to the current registration process. However, health research in the United States found that where an ethnic/cultural background question is built into systems over time this takes an average of 37 to 48 seconds and this time decreases where trust has been established. PIs report that it is more effective to ask service users this question at a subsequent meeting rather than the initial meeting (where possible).

Promoting equality through ethnic data collection

“A mainstreamed approach is sufficient when outcomes are identical for all components of the target groups; when evidence shows a clear gap between the situation of Roma and Travellers versus the rest of society (e.g. regarding their health and housing situation), policies should be adjusted and specific measures should also be developed.”

(European Commission Assessment of Ireland, June 2016)
APPENDIX I: GOOD PRACTICE SCENARIOS

The scenarios below have been designed to help PIs respond to queries that service users may have in relation to the ethnic/cultural background question. Please note that the suggested responses are not intended to be prescriptive and may not apply to all cases, rather they provide a framework for understanding and responding to the genuine concerns of service users about disclosing their ethnicity.
**Case 1: Samuel**

Samuel is unemployed and is seeking a SICAP supports. You have recorded his personal data and asked if he will provide consent to record additional sensitive data. He says that he thinks it is an invasion of his privacy and not relevant to accessing SICAP services or supports. He asks if this will have any effect on the standard of supports he will receive.

**SUGGESTED RESPONSE:**

Advise Samuel that you are required to ask this question to all service users as part of the programme’s registration process and for equality purposes. Reassure Samuel that the information provided:

- Will be kept confidential and anonymous so that he will not be identified, protecting his privacy;
- Will not be shared with any other department;
- Will not affect the standard of supports of services offered; and
- Will help plan services and make better use of resources.

Inform Samuel that he has the right to not answer this question. However, it is important to stress that the programme needs this information to make sure that it is meeting its legal obligation to promote equality and eliminate discrimination. This information will also help to make sure that resources for the service will continue to be provided.

**Case 2: Angelica**

Angelica is seeking a SICAP service/support and has provided consent to the recording of her sensitive data. Angelica explains that her parents both immigrated to Ireland from different parts of the world (mother is from the Philippines and father is from England). Angelica was born in Ireland and doesn’t know what group she belongs to. She asks you to decide what group she should select.

**SUGGESTED RESPONSE:**

Explain to Angelica that she must decide her ethnicity, that you cannot select an option for her. This would be a breach of data protection law and human rights standards. It could also lead to misclassification which makes the data less reliable.

Read out all options to Angelica or provide a card with a list of the categories and ask if she identifies with any of the categories. You can also remind Angelica that she can choose ‘Other, including mixed background’ option and write-in the group(s) she identifies with.
Case 3: Paulina

Paulina is seeking supports from SICAP. You have asked Paulina for permission to collect additional sensitive data. Paulina looks uneasy and asks why you need to collect that information.

SUGGESTED RESPONSE:
Advise Paulina that you are required to ask this question to all service users as part of the programme’s registration process and for equality purposes. The information will help the programme to know what groups are (and are not) accessing services and supports. Reassure Paulina that the information provided:

- Will be kept confidential and anonymous so that she will not be identified;
- Will not be shared with any departments or government officials, for example, the social welfare, Revenue, etc.
- Will help to make sure services are delivered in a way that meets her needs.
- Will make sure that certain groups are not excluded.

Case 4: Ioan

Ioan is looking for SICAP supports. You have collected Ioan’s personal details and asked for permission to collect further information. Ioan refuses and says that they do not collect this information in his home country and that it is against the law.

SUGGESTED RESPONSE:
Advise Ioan that you are required to ask this question to all service users as part of the programme’s registration process and for equality purposes to make sure that all groups are treated equally. Reassure Ioan that collecting this information is legal in Ireland once:

- You get his permission to record his answer;
- Ioan self-identifies his ethnic group;
- The information is collected for a specific purpose, in this case to make sure that groups are not excluded; and
- The information is made anonymous so that individuals cannot be identified.

Acknowledge Ioan’s previous experience in his home country noting that in some countries, services do not ask individuals to identify their ethnic group, but can answer the question on their behalf using markers such as clothing, skin colour, address, language, etc. This practice is not in line with human rights standards.

Inform Ioan that he has the right to not answer this question. However, it is important to stress that the programme needs this information to make sure that all service users have the same access to supports and services and to meet its legal obligation to promote equality and eliminate discrimination.
Case 5: Yasmin

Yasmin has given her consent to the collection of her sensitive data and you have asked her to select her ethnicity. You proceed to read out the categories on the IRIS form and she looks confused. Yasmin responds that her ethnicity is not on the list. Yasmin asks for an explanation why her ethnic group is not on the list and how she should answer the question.

**SUGGESTED RESPONSE:**
Advise Yasmin that the categories are the same as the census so that data can be compared nationally. The categories in the census achieve a high response rate as they are widely recognised. Explain to Yasmin that you cannot advise her how to answer the question, but if she does not feel that the categories reflect her ethnic background she can choose ‘Other, including mixed background’ option and write-in the group(s) she identifies with. [See note 14 & 15 for further information].

Case 6: Michael

Michael is looking for SICAP education supports. You have worked with Michael in the past on another project and know that he is an Irish Traveller. You record Michael’s personal details and he gives you consent to collect additional sensitive data. You ask Michael to identify his ethnic/cultural background question and he responds that he has already answered the previous ‘nationality’ question as Irish.

**SUGGESTED RESPONSE:**
Acknowledge Michael’s response to the nationality question. However, this question is asking about his ethnic/cultural background which is different and not determined by place of birth or passport. Describe ethnicity, proceed to read out all categories (and subcategories) and record his answer.
APPENDIX II

United Nations: A Human-Rights Approach to Data

1. SELF-IDENTIFICATION
- Voluntary self-identification (data collectors cannot ascribe ethnicity)

2. TRANSPARENCY
- A universal question; everyone is asked the question, not just minority ethnic groups

3. PRIVACY
- Data is only used for the purpose for which it is collected

4. DATA DISAGGREGATION AND COLLECTION BY POPULATION GROUP
- Data is analysed in consultation with organisations representing minority ethnic groups.

5. ACCOUNTABILITY
- Data is available to stakeholders in a timely manner

6. PARTICIPATION
- Active community participation and consultation with key stakeholder groups throughout the process in relation to:
  i. Definition of data collection purposes;
  ii. Categories;
  iii. Questions to be asked;
  iv. Actual collection of data (diverse enumerators/data collectors trained to deal with the sensitive issues relating ethnic data collection);
  v. Analysis and evaluation of the data collected; and
  vi. Dissemination of the data.
Endorsed by the Council of Ministers and adopted by the European Commission, the Ten Common Basic Principles on Roma Inclusion provide guidelines for Member States when developing and implementing strategies for Roma and Traveller inclusion. The principles are a tool for both policy-makers and practitioners managing programmes and projects. They provide a framework for the design and implementation of actions to support Traveller and Roma (and minority ethnic group) inclusion.

1. Constructive, pragmatic and non-discriminatory policies
2. Explicit but not exclusive targeting
3. Inter-cultural approach
4. Aiming for the mainstream
5. Awareness of the gender dimension
6. Transfer of evidence-based policies
7. Use of European Union instruments
8. Involvement of regional and local authorities
9. Involvement of civil society
10. Active participation of Travellers and Roma
APPENDIX IV:
PI Checklist

- Personal details have been recorded
- An explanation has been offered for the collection of additional sensitive information
- Confidentiality has been explained
- A clear rationale for collecting ethnic/cultural background has been provided
- The service user has provided consent and signed the data consent form
- A card with ethnic/cultural background categories has been presented OR all ethnic/cultural background categories have been read out to the service user
- Service user has disclosed their ethnic/cultural background
- The correct category has been recorded based on the individual’s response
- Outstanding queries or questions have been addressed