



## **Investing in People and Culture – Collaboration and Planning**

### **Background information about the RCO**

Our organisation is called Investing in People and Culture (IPC). IPC was formed in 2010 in recognition to the need for groups to work together at a grassroots level and in response to the government's Big Society and Localism agenda. IPC now has a working partnership with more than 25 refugee led organisations in the North east of England. Activities include:

- Organising awareness raising sessions
- Organising and facilitating training programmes
- Providing advice and information
- Signposting service users to supporting statutory and non statutory organisations
- Assist the integration of members with the British communities through cultural and social exchange activities/events
- Creating network and forming partnerships among RCOs and other agencies

IPC is run by volunteer executive management committee. We have currently no paid member of staff.

Our organisation would like to share the good and positive experience we have had when planning, organising, applying for funding, implementing and monitoring a small but exciting and pioneering project that dealt with the shortage of organ donations within the BME community in the region. The project specifically targeted refugees and asylum seekers and focused on issues such as cultural barriers, lack of knowledge, the process of organ donation and the issue of consent.

### **Consulting members and involving them in project development**

#### Origins of project

The idea emerged from the fact that people from the Black and Asian communities living in the UK are more likely to need a transplant (e.g. kidney) than the rest of the population. This is because people from these communities are more likely to develop diabetes or high blood pressure, both of which are major causes of kidney failure.

Unfortunately, while the need for donor organs is three to four times higher than among the general population, donation rates are relatively low among black and

South Asian communities, thus reducing the chance of a successful match being found.

The idea to tackle the problem occurred to a member of our organisation during a community event hosted by Newcastle Science City. He then floated the idea to apply for funding for community science projects to others in his community and was overwhelmed by the positive reaction – especially from one friend who had personal experience of someone close to him having needed a transplant in the past.

#### Conducting the consultation

We then conducted a series of focus group type consultation exercises to see if people are aware of the facts and if they would be interested in attending awareness raising sessions about the subject.

The consultation exercise started within the Eritrean community. First the management committee discussed the idea and determined that the idea seemed to be good, achievable and beneficial but wondered whether other members of the community would support it. Three leaders of the community were then assigned to go out and do some research. The aim of the research was to not only to collect information but to inform members of the proposed project and explain things. The leaders gathered people and conducted discussion groups. The discussions were not 'formal' meetings but informal conversations among active participants who brought stories and experiences of people they know within the community. The rest was done through word of mouth as the community is close tight knit community. Within few weeks, we knew that members of the Eritrea community would subscribe to the project.

We then encouraged leaders of other RCOs to do the same. They did the consultation exercise in their own way. Some mentioned the proposed project in their formal meetings. Others conducted formal focus groups facilitated by community leaders. Others did not need to do any consultations before they already 'knew' or believe the proposed project would be supported by the members of their community.

#### Results of our consultation

The outcome of the consultation was that people wanted to hear directly from Doctors and specialist nurses instead of professional trainers and consultants. They specifically wanted to know the organ donation process and how the national organ register works and the issue of consent. The result of the consultation exercise also showed that some of the participants' experiences have resulted in them having a wrong conception of organ donation. There were instances where doctors in some countries have actually taken organs from people without consent and sold them to wealthy people. As a consequence, they think if they ever consented to donate an organ in the UK, they would have to give it up while they are alive, and that it will be used for commercial purposes.

A summary report of the consultation exercise was sent to the NHS for the doctors and nurses to prepare a bespoke awareness raising session.

The same consultation exercise also showed that we were to organise social events lasting 2-3 hrs where traditional food is catered. Participants would be invited for a

social event with the aim of having a one hour and half slot for the topic. That was exactly what we did.

## **About collaborative/ partnership working with other organisations**

### Stage 1: Delivering awareness raising sessions

The collaboration work emerged out of personal friendships and professional relationships among the leaders of four / five RCOs: Somali community, Maranatha Assembly (a church group with a Charity Status that works with Ethiopian refugees), Congolese community and Eritrean community.

The idea of running a series of awareness raising sessions originated within the Eritrean community. The idea was then shared with other community leaders who immediately accepted the idea and were enthusiastic about it.

The leaders were then asked to go back to their respective communities and run consultation exercises to see if there was enough interest to organise similar sessions within their communities. The feedback from these groups was very encouraging. We then consolidated the ideas emerging from all the groups involved and wrote a simple funding application detailing exactly what the need was and how we were proposing to address the need. The application was immediately approved and we start to implement the project.

Implementing the project was the easy part. Leaders and volunteers from each community organised the entire project for their own respective groups.

### Stage two: Feedback and evaluation

Each participating RCO evaluated the sessions by distributing questionnaire to those that attended and the overall data was analysed. The results of the evaluation was then presented and discussed among the leaders and volunteers of the participating RCOs.

Analysis of the feedback from participants reveals that most of the participants would like to have more sessions, and that complimentary sessions were needed. People felt they did not have enough time to talk about the real reasons why people from their communities are not donating organs. So all the participating groups decided to put in a further funding application under IPC for additional 'Breaking Cultural Taboos' sessions with those groups that have attended the technical sessions delivered by the NHS specialists. The grant was approved. The aim was to talk among each other to identify and tackle cultural taboos in light of what we have learnt.

Such sessions made a real difference and produced the desired results. A number of people registered on the national organ donation register. This was because we were able to talk freely among ourselves in regards to tackling the cultural issues which the specialist nurses and doctors did not have the liberty to delve into. We talked and challenged each other for the scarcity of organs donation within our communities. We discussed religion, tradition and myths in detail.

The project was successful not only because of the genuine and identifiable need but mainly because it emerged from the consultation we carried out with many refugee community organisations in the region. Each participating community organisation

had consulted its members and came up with ideas of implementation. Volunteers from each community prepared the food, publicised the events, invited people and managed the smooth running of the project. As a result, the interest we all were able to create and the response from the respective communities was encouraging. At least 25 people were present at each session.

## **What problems and barriers did your RCO face in doing this, and how did you overcome or try to overcome these?**

### **About planning and implementing the project**

We did not encounter huge problems in planning and implementing the project. There were slight problems, however:

#### Lack of skills, knowledge and experience

Lack of skills, knowledge and experience of conducting consultation exercises was the main one. Some groups did not have the culture of consulting their members. The leaders used to come up with ideas and disseminate information using the 'top to bottom' approach. They lacked skills and experience of collecting, collating and analysing information. This problem was resolved by asking leaders / volunteers from other RCOs with experience of consulting their communities to 'skill up' those with less experience and support them in the actual collecting and analysing data.

#### Negative attitudes

During the consultation exercise we came across some people whose personality was negative and pessimistic. Even though they were raising some legitimate and important issues and it was within their right to say the project will never work, they emotionally drained some people, made the consultation atmosphere uncomfortable for people and actively discouraged people from taking part. We resolved the problem by introducing strict guideline which specified the need to be democratic but also firm. The strategy seems to have worked.

#### Attempts to standardise implementation

At the beginning of the project we tried to standardise implementation by having the same structure of delivery and having the session at one community venue. This was outside the spirit of the collaboration and was quickly scrapped. Each community organised their own activities but we used the same evaluation methods for all groups.

### **About collaborative/ partnership working with other organisations**

The organ donation project was made possible by the collaborative work of various independent RCOs which are active in the North east of England at the present. IPC creates an environment where the leaders of these RCOs are able to share ideas, plan projects, apply for fund and implement projects collectively either under the umbrella of IPC or under loosely connected partnerships and joint ventures between two or more RCOs. IPC is now increasingly becoming a 'consortium' of RCOs that wish to work together. This presents a challenge which was highlighted in this project:

- There was no formal partnership agreement that specified what each partner should do.

- Some members of the community that originated the idea felt that the project was usurped by other communities and were not happy because others were 'involved too much'. It was explained to them that the more other RCOs get involved the more communities will benefit and that funders like it that way.
- At the beginning of the project (stage 1), a community group left the project because they had personal issues with some leaders within the 'partnership' and they 'did not understand what was going on'. We tried to resolve the issue by having a discussion among all the groups with no avail. The remaining participating groups clubbed together and organised a combined session which went very well indeed.

## **We learned the following key points from this work**

### Involving community members

- **Encourage people to get involved from the outset.** Projects will only succeed if they are based on what people need and want. A genuine need may not be enough if people don't want to take part. If people feel that they have ownership of what is being offered by a project, they will make it a success. If projects are planned using the 'bottom up' approach, their implementation will be easy. Involving project participants will require preparing to change / abandon your own ideas and let emergent ideas shape the trajectory of the project.
- **Encourage diversity of ideas to emerge but stress on having a common purpose.** Otherwise the project could lose focus and become clumsy and unmanageable.
- Respect individual ideas and accept people have the right to voice their opinion however disagreeable they may be.
- Project participants should be involved not only with idea generation and planning but also with implementation and evaluation of a project.

### Working with other organisations

- Have a written agreement (however informal) when working with other groups even if it is for a one-off joint venture project. Personal friendships and professional relationships do not suffice and could only take you so far. Written agreement will settle any arguments or disputes however small they may be.
- Personal relationships among participating (partnering) groups should be managed properly. As leaders in any sphere of life, leaders for the refugee communities are strong characters with strong personality having strong opinions about almost everything.
- Whenever possible, try to compromise and support others
- Be fair and transparent

## **Our tips for other RCOs thinking of delivering something similar**

We suggest people consider the following tips if they are thinking of delivering similar project (e.g. organ donation).

1. **Have evidence based identifiable needs.** We based our project on sound evidence. For example, only one per cent of black people in Britain are signed up to the NHS Donor Register – but, due to increased rates of diabetes and high blood pressure, they are three to four times more likely than the general population to need a kidney transplant. Having sound evidence from a respectable source provides your project with legitimacy and demonstrates that your organisation approaches projects in a structured and professional way.
2. **Consult your target people before you write the application for funds.** Due to various reasons to do with country of origin, history, culture and religion, organ donation is very personal and sensitive issue. If people are not consulted from the outset and own the project, it is unlikely they will take part in it. The NSH has tried and failed to penetrate this group.
3. **Use examples of people** within the community that have benefited from organ donation and those who died due to lack of organ donor. People respond to real life scenarios. Always handle the matter with care and sensitivity, however.
4. **Projects can bring about long term change by challenge inaccurate perceptions.** People think wrongly that their religion opposes donating organs. To the contrary most major religions in the UK actively encourage their members to register on the nation organs donation register.
5. **The application should be simple, clear and should detail the costs for each activity.**
6. **Demonstrate you are able to manage and deliver the project by showing a good track record in handling, recording, keeping receipts and reporting financial operation**
7. Work in collaboration with likeminded people and organisations to reach as many communities as possible. In this economic climate funders are looking for projects that deliver value for money and they will favour collaborative work where the overhead cost is minimum for maximum impact.