



Building Self Advocacy Experts by Experience

Experts by Experience

Capstone Project 2023
Master in International Development
IE University

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Agenda

01 Context & Challenge

02 Methodology

03 Literature review

04 Participants' Interviews

05 Conceptualisation of measurement guidelines

06 Limitations and recommendations

07 Questions

01 Context & Challenge

Refugee Reception Crisis in Greece

Refugee population increase

Source: World Bank 2023

1,443  **119,650**
2010 2021

Reception policies resulted in a complex humanitarian situation

Source: Human Rights Watch, 2022

- Pushback of migrants
- Homelessness
- Lack of access to healthcare
- Rising violent incidents among the affected population

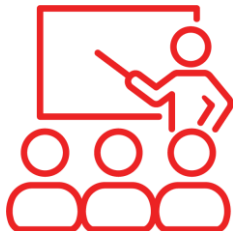
MSF has been advocating for the rights of refugees by calling out Greece and the EU for their actions

The Experts by Experience Model

The EBE pilot was launched by MSF's Victims of Torture Rehabilitation Clinic in Athens in July 2018, focused on enabling participants to advocate for desired changes.



Provides a **platform** for participants to come together, and organize.



Offers **training** in advocacy and community engagement.



Supports the development of advocacy **strategies** and facilitates **access to key stakeholders**.

The main challenge

How might the impact measurement model be enhanced to facilitate further development of the EBE model?

The current measurement methods assess the success of the project by solely evaluating the levels of participation and engagement. It does not account for how success or impact is perceived by the participants.

02 Methodology

Methodology

Phase 01

Literature
review



Identify, suggest, and analyze relevant literature on self-advocacy and innovative measurement models.

Deliverables:

- Literature review report.
- Literature review library.

Phase 02

Participant
Interviews



Get a first-hand understanding of success looks like to the participants in the EBE model.

Deliverables:

- Participants Interview guideline.
- Participants Interview responses.
- Participants Interview conclusions.
- Considerations for improvement.

Phase 03

Conceptualisation of
measurement guidelines



Develop guidelines on how to measure impact of the EBE model on participants and their community.

Deliverables:

- Measurement guidelines
- EBE survey
- Final report

03

Secondary Collection of Data: Literature Review

Literature review

01 Internal literature review of the EBE project documents.

02 Sit-downs with internal stakeholders.

03 External literature review and analysis (Self-advocacy, Impact Measurement, EBE)

MSF Capstone

Literature review library

Interview Collection

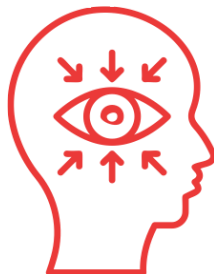
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	A Name	A Author	A Source	URL	Focus	Tags2	Key points
11	Role of the media	Eirini Kalafati	Open Educational resourc...	http://essay.uwaterloo.ca/...	Context	media	media framing affected I
12	Media on raising awareness and p...	Anders Ravik Jupskås, M...	Project Muse	https://muse.jhu.edu/artic...	Context	media	Media on the one hand p
13	Greek and EU citizenship	Heath Cabot	Research Gate	https://www.researchgate...	Context	marginal players	Greek citizenship and EL
FOCUS: Self-Advocacy Count 5							
14	ASK anais	Steven Kane Curtis, Jagd...		file:///Users/anaisarnopou...	Self-Advocacy		• Social exclusion ca
15	Speaking up: a model of self-adv...	Mariel A. Pfeifer, Eve Mel...	International Journal of S...	https://jstemeducationjour...	Self-Advocacy	Components	• Using Test's conce
16	Self-Advocacy as a Means to Posi...	Sian Anderson, Christina ...	Journal of Applied Resear...	https://www.researchgate...	Self-Advocacy		• Study explored the
17	The Effect of Patient Self-Advoca...	Leslie Ramos Salazar	Communication Studies J...	https://self-compassion.o...	Self-Advocacy		-H1: After controlling for
18	A Conceptual Framework of Self...	Teresa H. Thomas, PhD, R...	National Library of Medic...	https://www.ncbi.nlm.nih...	Self-Advocacy		Specific self-advocacy t
FOCUS: Measurement Models Count 14							
19	Recent advances on impact meas...	Marie J. Bouchard, Damie...	Wiley Online Library	https://onlinelibrary.wiley...	Measuremen...	Trends	• In the recent deca
20	Nine trends in social impact meas...	Danielle Kutchel	ProBono Australia	https://probonoaustralia.c...	Measuremen...	Trends	1. Shift towards outc
21	Taking a Human-Centered Approa...			https://www.madnow.com...	Measuremen...	Human-centered	• Reporting systems
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Self-Advocacy



Organisations should adopt a comprehensive approach to self-advocacy, addressing **multiple levels of influence**: individual, interpersonal, and institutional factors.



Through self-advocacy groups, the participants can **change the perception of self** and how their community sees them.



Self-advocacy is a key element in breaking the **decision-making process feedback loop**.

Impact measurement

Trends

**Increase in
impact metrics
and frameworks**

**Data revolution
has enhanced
our ability to
track, analyze,
and report**

**Mixed-method
approach
increased
acceptance**
(qualitative and
quantitative data)

**Human-Centered
Design (HCD)
approach to
reflect value and
impact by
beneficiaries.**

**Shift from
evaluation alone
to continuous
learning and
improvement**

Best practices

✓ Focus on outcomes rather
than outputs or activities.

✓ Avoid Vanity Metrics

✓ Build for action and
decision-making

04

Primary Collection of Data: Participants' interviews

Participants' interviews

- 01 Design interview guide
- 02 Conduct In-depth Interviews
- 03 Interview Analysis

Profiles:

Four selected participants by MSF that had been part of different cohorts in the pilot.

Interview Plan

As part of the AI University Capstone Project on the Experts by Experience model, and after conducting a literature review on self-advocacy and innovative measurement models, we will be conducting interviews to gain a firsthand understanding of various issues for the participants and developing guidelines to ensure that success and improve the EBE model in relation to the participants' goals.

01 Interview Objectives

- Understand the context of the participants of the EBE model.
- Understand the interests of participants in the EBE model, as well as the benefits they find of being part of it.
- Understand what the success of the EBE model looks like for participants in terms of goals and outcomes.
- Identify possible expectations for the EBE model by an understanding of current needs.

02 Interview Guidelines

- Interviews will be conducted in pairs, one will conduct the interview, while the other will take notes and contribute with follow-up questions.
- The interviews will be held online via Zoom or WhatsApp Call depending on the participant.
- Interviews will take from 1 hour to 1.5h.

Time	Section	Questions
5'	Introduction to the interview	Our names are Ivan and we are students of the Master in International Development at UCLouvain, in Brussels, Belgium. Thank you for your participation in the interview which is part of our research thesis, with the aim of understanding how the EBE model is doing and how it can be improved. We will electronically record the interview unless you prefer not to have it recorded and supported. You can contact us if you have further questions after the interview. It is going to last 1h - 1h.5h. It is going to be leading the interview and XXX is going to be taking notes.
10'	Participant's introduction Goal: Understand the context of participants	Please tell us a bit about yourself: What is your name, how old are you, where are you from? What do you do for a living? How long have you been in Belgium?
15'	Introduction to EBE model Goal: Understand if/according, starting needs, and expectations.	Can you tell us a little bit about how you entered the Experts by Experience model? (Did you who, where, and how?) We want to know what made EBE model attractive for you. From the following options which influenced your decision to participate? (Please tick) - Opportunity to learn - A safe space to talk - Trust in MSF - Personal connections from other participants - Interest in other participants Is there another factor that influenced your decision to participate?

Interview Collection

Table 1: Interview Collection

Views	Grid view	Hide fields	Filter	Group	Sort	Color	Share and sync
1	Elvina Kurumad	Participants background	How did you get into EBE	Attractive factors	Expectations		
2	Mariana Sola	Participants background	How did you get into EBE	Attractive factors	Expectations		
3	Guinevere Dials	Participants background	How did you get into EBE	Attractive factors	Expectations		
4	Mamadou Dials	Participants background	How did you get into EBE	Attractive factors	Expectations		
5	Conclusion						



1. The EBE Model is first and foremost a safe space

A space where “you are **free** not to say anything”

A **supportive environment** to learn and acquire new soft skills

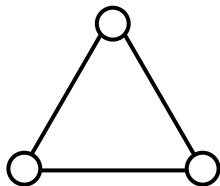
A **transformative journey** - a “healing process”

BUT,
No common definition
of the EBE and no
mentioning of ‘self-
advocacy’

2. Success is multifaceted

Development of self-confidence

Participants feel empowered to express themselves comfortably and effectively communicate their experiences and needs



Sense of belonging

Participants feel they belong to a community of mutual support and understanding

External advocacy

Participants have the ability to engage with and influence individuals and organisations beyond the immediate EBE context

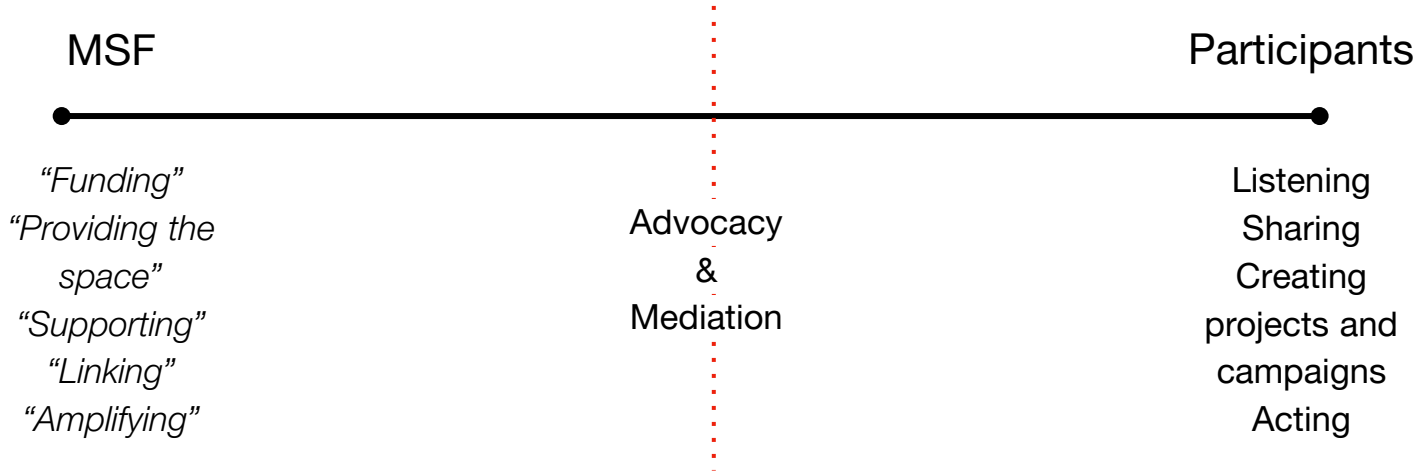
3. Onboarding relies on trust, rather than knowledge of the full value

Main appeal: could get to know people that had been through similar experiences

Key enabler: trust in MSF

BUT,
Participants usually do not understand the whole EBE purpose before joining

4. The line between the participants' and MSF's role is not clear for all



Considerations for further development of EBE

1. Establish a common understanding and definition of EBE

Proposed mechanisms:

- Incorporate a comprehensive onboarding
- Initiate reflection sessions
- Measure the participant's understanding

2. Delineate the boundaries and roles within the EBE model

Proposed mechanisms:

Encourage participants to take ownership of their experiences and initiatives and become more autonomous

3. Measure beyond participation and engagement

Include three different levels:

- Adoption of self-advocacy skills
- Community Engagement
- Action-taking within their environment

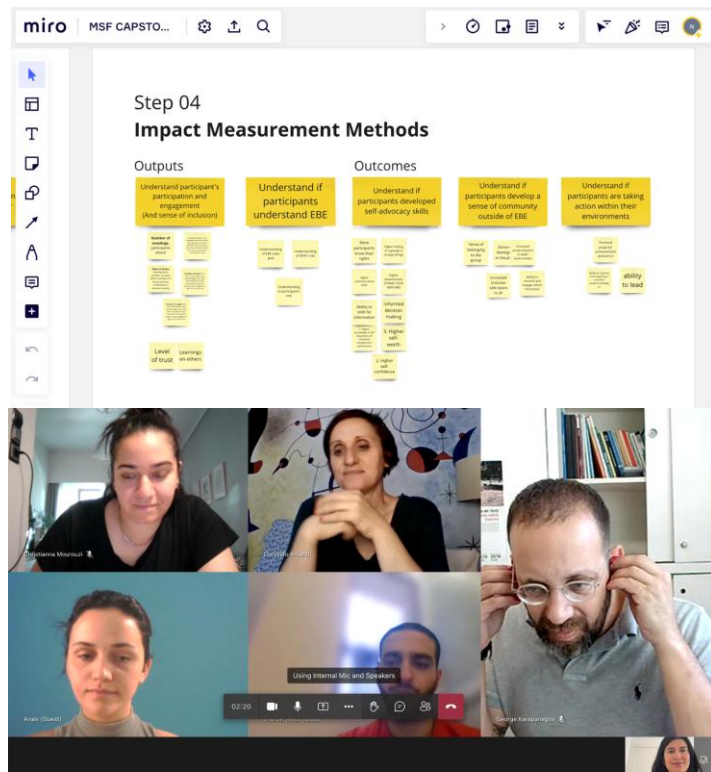
05

Conceptualisation of measurement guidelines

Impact measurement guidelines

- 01 Definition of impact targets
- 02 Definition of measurement goals
- 03 Definition of indicators, metrics, and measurement methods.

Guidelines were drafted by us and consulted and improved with MSF.



The screenshot shows a Miro board titled "Step 04 Impact Measurement Methods". The board is divided into two main sections: "Outputs" and "Outcomes".

Outputs:

- Understand participants participation and engagement (and sense of inclusion)
- Understand if participants understand EBE

Outcomes:

- Understand if participants developed self-advocacy skills
- Understand if participants develop a sense of community outside of EBE
- Understand if participants are taking action within their environments

The board also includes a sidebar with various tools and a bottom section with a video call interface showing four participants: Yasmine Mounir, Yasmine Mounir, George Karavassios, and Anah (Guest). The video call interface includes a timer (02:20) and a status bar at the bottom.

Impact targets



Target group

Vulnerable populations
and patient groups associated
with MSF beyond refugees
victims of torture.



Breadth of Impact

Reach 100 participants
across 6 to 10 teams operating
in diverse contexts.



Depth of Impact

The focus at the moment is not
the change in policy, but the
change in the participants:
capacity and community building.

Impact Measurement Objectives

01

Assess
**Participation
and Engagement**

New

02

Measure
Participants'
**Comprehension
of EBE**

Expanded

03

Evaluate
Development
of Participants'
**Self-Advocacy
Skills**

Expanded

04

Measure
**Formation
of Community**
Beyond EBE

Expanded

05

Assess
Participants'
Action-Taking

1. Assess Participation and Engagement

Indicators	Metrics	Measurement Method	Sources
1.1 Attendance rates at EBE program sessions.	Percentage of program sessions attended.	Number of sessions attended / Total number of scheduled sessions x 100.	Attendance sheet (monthly) Mediator follow-up sheet (monthly): a tracking document that allows mediators to record the behaviours and progress of the participants in the meetings.
1.2 Active participation in group discussions and activities.	Frequency of participation in group discussions and activities.	Qualitative scale rated by MSF mediators (Low, medium, high)	
1.3 Level of contribution to collaborative projects or initiatives.	Frequency of contribution in projects and initiatives.	Qualitative scale rated by MSF mediators (Low, medium, high)	
1.4 Inclusion and involvement in decision-making processes within the program.	Level of involvement in feedback meetings and discussions for improving the EBE model.	Qualitative scale rated by MSF mediators (Low, medium, high)	

2. Measure Comprehension of EBE

Indicators	Metrics	Measurement Method	Source
2.1 Understanding of the purpose and principles of the EBE model.	Level of understanding the purpose and principles.	True or false statements answered by participants.	EBE Survey (after the cycle is over)
2.2 Understanding of the role of MSF in the EBE model.	Level of understanding of MSF's role.	True or false statements answered by participants.	
2.3 Understanding of the role of participants in the EBE model.	Level of understanding of participant's role.	True or false statements answered by participants.	

EBE Survey Example Questions

Please select if you believe the following statements are true or false.

- The EBE model is a self-advocacy program.
- The EBE model strives to foster capacity building, promote the empowerment of individuals to articulate their own needs, and enhance their daily lives.
- The EBE model fosters the formation of supportive communities centered around shared experiences.
- The EBE model is a campaign in which MSF advocates for affected populations.
- MSF's role in the EBE model is to advocate for people like me.
- MSF role is to provide me with the necessary tools and knowledge to advocate for myself.
- My role in the EBE model is to listen and share my experience.
- My role in the EBE model is to contribute and plan self-advocacy campaigns or projects.

3. Evaluate Development of Participants' Self-Advocacy Skills

Indicators	Metrics	Measurement Method	Source
3.1 Knowledge of specific rights relevant to their circumstances or community.	Percentage of proficiency in knowledge of specific rights.	True or false statements.	EBE Survey (after the cycle is over)
3.2 Self-confidence in their abilities to make a difference or create change.	Level of self-confidence in their abilities to make a difference.	Likert qualitative scale assessed by the participants (1 to 5).	
3.3 Ability to communicate personal needs and boundaries.	Level of confidence in expressing their needs and boundaries.	Likert qualitative scale assessed by the participants (1 to 5).	
3.4 Verbal communication skills.	Level of confidence in communication skills.	Likert qualitative scale assessed by the participants(1 to 5).	
3.5 Understanding of their personal strengths and weaknesses for self-advocacy.	Level of understanding of their strengths. Level of understanding of their weaknesses.	Likert qualitative scale assessed by the participants (1 to 5).	
3.6 Self-esteem and a positive perception of their own value.	Level of self-esteem.	Likert qualitative scale assessed by the participants (1 to 5).	

EBE Survey Example Questions

Please rate the following statements on a scale of 1 to 5
(1 being “strongly disagree” and 5 being “strongly agree”)

- I feel confident in my ability to make a difference thanks to the EBE experience.
- By participating in the EBE experience, I have become confident enough to express my needs and boundaries.
- I feel like my level of autonomy has increased since joining the EBE programme.
- I feel confident in my communication skills thanks to EBE.
- I feel like my ability to make informed decisions has increased since I have joined the EBE.
- Through the EBE programme, I have developed an understanding of my strengths.
- Through the EBE programme, I have developed an understanding of my weaknesses.
- By participating in the EBE experience I have improved my self-esteem.

4. Measure the Formation of Community Beyond EBE

Indicators	Metrics	Measurement Method	Source
4.1 Sense of belonging in the context they live in.	Level of belonging in the context they live in.	Likert qualitative scale assessed by the participants (1 to 5).	EBE Survey (after the cycle is over and 6 months later)
4.2 Participation in community activities and events.	Number of activities and events they have participated in.	Number of times assessed by the participants.	
4.3 Ability to mobilize or inspire others to join causes, initiatives, or activities.	Level of confidence in their ability to mobilize or inspire others.	Likert qualitative scale assessed by the participants (1 to 5).	
	Number of circumstances in which they have succeeded in mobilizing others.	Number of times assessed by the participants.	

EBE Survey Example Questions

Please rate the following statements on a scale of 1 to 5
(1 being “strongly disagree” and 5 being “strongly agree”)

- I feel like I belong in the community I live in.
- I feel confident in my ability to mobilize or inspire those around me.

How many activities or events have you participated in outside of the EBE context?

How many times have you achieved in mobilizing other people towards a common objective?

5. Assess Participants' Action-Taking in their Environments

Indicators	Metrics	Measurement Method	Source
5.1 Ability to organize and initiate self-advocacy projects/campaigns	Level of proficiency in organizing and initiating self-advocacy projects Number of projects/campaigns they have organized or initiated.	Likert qualitative scale assessed by the participants (1 to 5). Number of times assessed by the participants.	EBE Survey (after the cycle is over and 6 months later)
5.2 Ability to lead others towards common goals	Level of confidence in leading others towards common goals Number of times they have led others towards their goals.	Likert qualitative scale assessed by the participants (1 to 5). Number of times assessed by the participants.	
5.3 Ability to execute or implement self-advocacy projects/campaigns	Proficiency level to implement self-advocacy projects/campaigns Number of projects/campaigns they have implemented.	Likert qualitative scale assessed by the participants (1 to 5). Number of times assessed by the participants.	

EBE Survey Example Questions

Please rate the following statements on a scale of 1 to 5
(1 being “strongly disagree” and 5 being “strongly agree”)

- I feel highly proficient in organizing and initiating self-advocacy projects
- I feel confident in my ability to lead others towards common goals
- I feel highly proficient in implementing self-advocacy projects/campaigns

How many projects or campaigns have you organized or initiated?

How many times have you led others towards common goals?

How many projects or campaigns have you implemented?

06

Limitations and Recommendations

Limitations & Recommendations

1. Current focus on short to medium-term impact, **lacking evaluation of long-term results** like policy changes.



Include methods to assess long-term systemic impact **once short and medium term goals are reached.**

2. Reliance on qualitative scales assessed by participants themselves can **lead to subjective and potentially biased responses (Social desirability bias).**



Ensure **anonymity and confidentiality**, emphasize the importance of honest responses, **cross-reference** with external observations, and complement the surveys with **focus groups and interviews** for deeper understanding and improvement of the model.

Limitations & Recommendations

3. Potential attrition due to existing challenge of participant engagement.



Reach a **higher number of respondents** to ensure a representative sample size, and implement regular **follow-ups and incentives**.

4. Lack of testing and based on small sample of pilot participants.



Conduct a **pilot**, gather **feedback** (from participants and EBE staff), and **iterate** guidelines.

5. Concerns about increased workload for data gathering, analysis, and reporting.



Prioritize indicators based on the moment and context, adjusting the methods accordingly to ensure efficient implementation.