A young person's guide for researchers: Co-producing data research with under-served groups

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Date: August 2024

What is co-production and why should you do it?

Co-production of research is where researchers and experts by experience work as equal partners throughout a research project, sharing power and decision-making.

Experts by experience (who have direct experience of the thing you are researching) have the right to be involved in data research. Their lives make up the data so they can help you better understand the stories behind it and help your research make a positive impact in people's lives.

Here are some handy dos and don'ts for researchers who want to co-produce data research with experts by experience.

Before you start

✓ DOS

GET A PARTNER
Partnering with an advocacy or charitable organisation can connect you to experts by experience. A trusted partner can help everyone feel more comfortable and supported, especially with sensitive topics.

GET FUNDING
Co-production needs to be properly resourced.

THINK ABOUT MUTUAL BENEFIT
Everyone brings something to the table, so everyone needs to get something out of it.

CONSIDER GROUP SIZE
How will it affect levels of participation and group dynamics? How representative will it be?

DON'TS ✗

BE AFRAID TO TRY
Not everyone will be convinced, but sometimes new approaches must be tested to persuade others.

OVERTHINK IT
There is no single, perfect way to do co-production. Make a start and learn and develop the approach together as you go.

TREAT IT LIKE A TICK-BOX EXERCISE
Make sure you and your team are properly invested in the work. And be passionate and open-minded!

ASSUME YOU KNOW BEST
One type of knowledge or experience isn't above the other.

During ✔️ DOS

PRIORITISE GOOD RELATIONSHIPS
Make everyone feel welcome and allow time and space to get to know each other. Be willing to learn from others, compromise, and work together to overcome obstacles.

BE OPEN ABOUT THINGS YOU CAN'T DO
Explain what data and data research is. Be upfront about what data is and is not available, and where lived experience experts can and cannot be involved (e.g. no public access to confidential data in safe settings).

CO-CREATE HOW THE GROUP WILL RUN
Things like group agreements, meeting times / places and training needs should be decided together.

FACILITATE RATHER THAN DICTATE
Share decision making and be willing to change your approach if needed.

CREATE AN EQUAL PLAYING FIELD
Use different techniques to accommodate everyone's strengths. Value all contributions and make sure no one is left behind.

CELEBRATE SUCCESS
Reflect on progress, recognise achievements and wins along the way.

DON'TS ❌

USE JARGON OR COMPLICATED WORDS
Instead, communicate clearly and make your research as accessible as possible. Understanding data and statistics is hard so you will have to find ways to simplify complex information.

EXPECT TOO MUCH TOO SOON
Participation and understanding take time. Be patient. Give people choices and time on complex topics.

CATCH PEOPLE OFF-GUARD
Give people advance warning of difficult topics. That way, they can opt-out if they are uncomfortable. Make sure support is available.

HAVE IT ALL YOUR WAY
Avoid being too prescriptive or pushing things the way you want.

MAKE ASSUMPTIONS
Don't speak for/over experts by experience. Listen and learn from them instead.

CRAM TOO MUCH INTO A SESSION
This could leave you and your group feeling overwhelmed, and the process won't be as rewarding.

Remember!!
Co-production is about giving a voice to the people whose lives make up the data. Nothing about us without us!

If you want to learn more about co-production, <u>check out these resources.</u>

About the author
The author is the ADRC NI Research Assistant (internship) and a member of the Data Research Advisory Group (DRAG). DRAG co-produce data research related to care experience.

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