Dissemination Guide

Take simple steps to widen reach and increase trust by including study participants and communities in your dissemination plans.

PAIR & CHIBE

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Introduction to the Guide

Welcome! We are so happy you want to learn how to incorporate sharing results with your study participants and community stakeholders into your research practices.

This resource guide was put together by the Joint Research Practice Working Group (JRP). The JRP was chartered in 2021 by the Center for Health Incentives and Behavioral Economics (CHIBE) and the Palliative and Advanced Illness Research (PAIR) Center at the University of Pennsylvania, Perelman School of Medicine. Its charge is to develop and disseminate evidence-based, best practices and guidelines for the conduct of research that includes people from all backgrounds and represents the communities we serve to advance the science and practice of health equity.

Dissemination comes in many different forms.[1] As academic researchers, we routinely disseminate study findings through published papers in academic journals, at conferences via oral or poster presentations, and through media exposure. This guide is designed to help you think through how you can develop and execute a dissemination plan that includes sharing results directly with additional important stakeholder groups: the participants of your research studies and the communities impacted by the topic of your research.

This guide is intended to complement your existing dissemination plans to make them even more impactful. Throughout this guide, we will address the rationale for sharing results with participants; considerations for developing your dissemination plan; pathways for dissemination, along with illustrative examples; how to incorporate language about sharing results with participants into your grant proposals, IRB protocols, and consent processes; and an example of a ready-to-use template for reaching out to participants via mail or email.

Executive Summary

Principles

A. Participants are a key stakeholder group
B. Disseminate results to all relevant stakeholders
C. Specific plans for dissemination will vary for each stakeholder group

Key considerations

A. **Mode**: How will you share the results?
B. **Timing**: When will you share the results?
C. **Context**: What factors should be considered when interacting with your stakeholders?
D. **Partnerships**: Are there community organizations or others with whom I am working that can help disseminate the results?
E. **Sensitive findings**: Should your results be shared publicly or only with specific groups?

When writing a dissemination plan, define:

A. **Who**: define your audience and who is responsible for the dissemination plan
B. **What**: identify the messages that need to be disseminated
C. **Where**: identify the appropriate venues to disseminate your messaging
D. **Why**: identify the purpose of dissemination to each stakeholder group
E. **When**: establish a timeline
F. **How**: select your tools, methods, and approach for disseminating messages

Tools and approaches:

A. Combine tools and approaches in ways that make sense for each stakeholder group. Some examples include:
    a. Mailed letters
    b. Emails
    c. Infographics
    d. In person
    e. Websites
    f. Videos

Tips for creating accessible content

A. Use clear plain language
B. Avoid jargon and technical terms
C. Limit sentences to 8-10 words
D. Break up content into short paragraphs
E. Use infographics or visuals

Using this Guide

1. **Familiarize** yourself with why dissemination to participants and community stakeholders is important.
2. **Learn** about important considerations and components of dissemination plans.
3. **Review** the appendices for additional resources, FAQs, a dissemination "quick guide," and numerous examples from real studies.
4. **Discuss and develop** a dissemination plan with your team. You can use the stakeholder analysis tool in the section on Dissemination Planning: Stakeholder Analysis (see pp. 16-17).
5. **Consult** the JRP when you need a helping hand. Should you have questions or need help, do not hesitate to reach out to us at jrp@pennmedicine.upenn.edu. The JRP's Practicing Equitable Research and Knowledge Sharing (PERKS) consultations are a quick and easy way to chat with someone about the challenges you face when striving to conduct equitable research. We will listen and share strategies based on the evidence and our lived experience conducting research at Penn.

What we do not cover in this guide

You may be familiar with the concept of returning individual results to participants, sometimes referred to, in shorthand, as "return of results." This may include the results of blood tests, imaging, identified biomarkers, and more. While the importance of returning individual participants' results to the person and/or family is increasingly recognized, the JRP is not well-versed in this topic, which differs greatly from sharing aggregate results to participants as a group or with the greater community. You can learn more about returning individual results in a 2018 Joint Report from The National Academies of Sciences, Engineering, and Medicine.[2]

Importance of Sharing Results with Participants & Community Stakeholders

Why dissemination matters

The World Medical Association (WMA) periodically reviews and amends the Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Participants. Although previous versions discussed the importance of making results publicly available, provisions specific to human subjects enrolled in studies are newer, Dissemination of results was first included at the 64th WMA General Assembly,[3] held in October 2013, as noted in Article 26:

> *All medical research subjects should be given the option of being informed about the general outcome and results of the study.*

During the 75th WMA General Assembly,[4] held in October 2024, the most recent amendments expanded their guidance to include the following about participants and their communities in Article 6:

> *Meaningful engagement with potential and enrolled participants and their communities should occur before, during, and following medical research. Researchers should enable potential and enrolled participants and their communities to share their priorities and values; to participate in research design, implementation, and other relevant activities; and to engage in understanding and disseminating results.*

Researchers using both quantitative and qualitative studies have identified sharing results as important. One study demonstrated that as many as 90% of participants surveyed said they would like to know the results of a study they enrolled in.[5] From focus groups, researchers learned that participants felt study teams should always offer to share research findings at the participant and community levels.[6] Despite this, many participants receive little to no communication after contributing to research, which can leave them feeling disconnected from the outcomes of their contributions. In fact, less than 1/3 of clinical trials share results with participants and community stakeholders.[7]

Disseminating results to a wide variety of stakeholders, including participants and the community, amplifies the uptake and impact of researchers' work. Participants act as one such amplifier, as they report sharing results with people in their personal networks, including doctors, friends and family, and others with similar medical conditions.[8] Sharing results has benefits both for those conducting and those participating in human subjects research:[6, 9]

A. For participants:
    a. Increases a sense of ownership and engagement
    b. Provides opportunities for learning and reflection
    c. Builds trust with research teams
    d. Helps participants understand the impact of their involvement

B. For research teams:[6, 10]
    a. Enhances participant trust and goodwill
    b. Encourages future participation
    c. Demonstrates commitment to ethical research practices and respect for participants

Hear from real people!

A recent survey conducted by the BETTER Center, within the PAIR Center, solicited participant preferences and advice for conducting research with underrepresented groups. The survey included open-ended and multiple-choice questions.

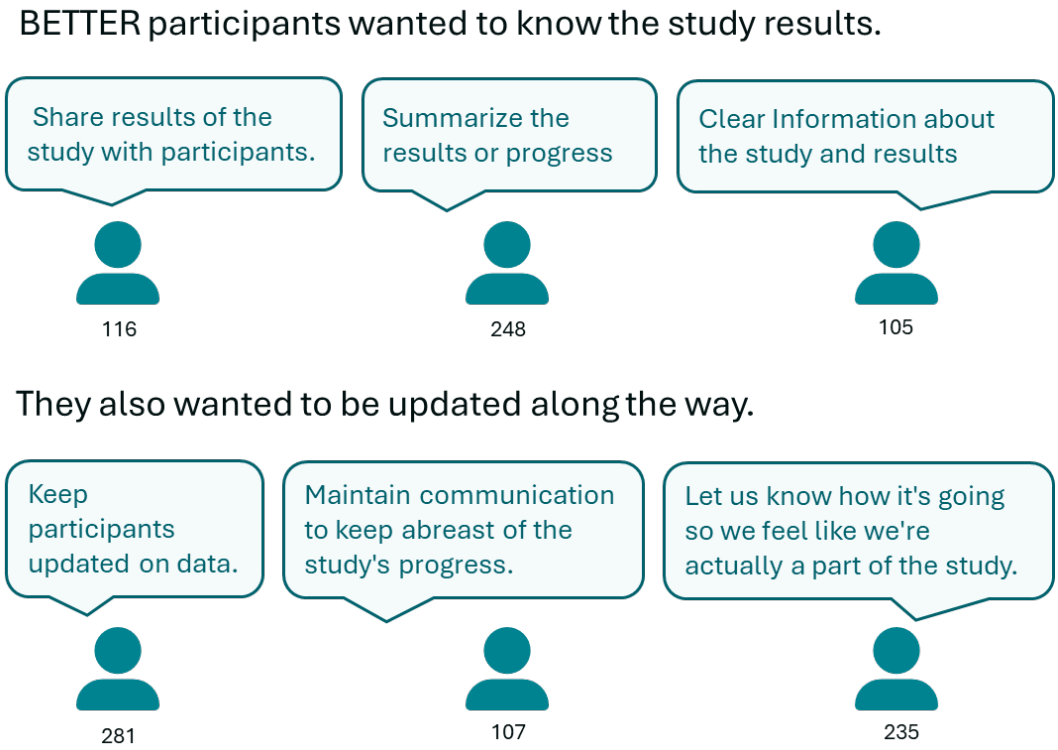
Survey respondents who identified as women, Black, Latinx, and/or rural-dwelling thought it was important for study teams to share results.

Qualitative Data

We asked participants to offer us advice to help people agree to participate in a research study. Then we asked them to **share things we should do.**

We also asked them to imagine someone asking them to participate in a research study, and **share things that would make them agree to participate.**

There were lots of things they recommended research teams do, and many motivators to participation. We learned that one of the actions research teams can take is to share the results.



Quantitative Data

We asked: What type(s) of support would make it more likely that you participate in a research study (do not include money)?

Participants said: Overall, 46% said getting results would increase the likelihood of participating. Latinx participants were particularly motivated by knowing results would be shared (57%).

Group	*Percentage*
Women	49%
Black	33%
Latinx/Hispanic	57%
Rural	47%
All participants	46%

Considerations for Effective Dissemination

When planning to disseminate study results, consider the mode, timing, context, partnerships, and whether your findings are sensitive.[6] These considerations are applicable to dissemination to all groups, not just participants and communities. We highlight examples of how these considerations might manifest in your dissemination plans with examples.

Mode

How will you share the results?

A. Examples of mode include in-person, via phone or video call, through mailed materials, or electronically such as through email.
B. Depending on your point of contact, you may use different types of media, such as videos, letters or handouts, infographics, or a combination of types.[6]
C. Consider modes that make sense for your participants and are achievable for your research staff given your resources.[9]
D. Study examples:
    a. Your study coordinator communicates regularly via email. You may choose to email a letter with an embedded video or infographic and include links to further resources.
    b. You recruited participants in person from four local assisted living facilities. You may choose to have research staff on site presenting to the residents and provide a printed one-page summary.

Timing

When will you share the results?

A. Usually, you will share the results once your study activities and analysis are completed.
B. In addition to final results, participants value updates on a study's progress.[6]
C. Study teams should consider whether they want to align sharing results with participants with publishing dates of peer reviewed papers.
    a. Study example: Participants are professionals in the field of your research; you might send an email with a link to a published manuscript.

D. You may be able, and want to, share interim findings before you have final results. Early sharing may be beneficial in some contexts. Be aware of limitations based on your study design or funder.
    a. Study example: Study participants eager to help disseminate the results to other participants or stakeholders can serve as powerful advocates for the findings.

Context

What factors should be considered when interacting with your stakeholders?

A. Adapt content and format to meet their needs and communication preferences.[6, 9]
B. Study examples:
    a. You're doing a study with older adults who may have less access to technology or limited digital literacy. Additionally, you already have mailing addresses collected from sending enrolled patients a welcome packet. You decided to send results via mail rather than through email or a website post.
    b. You utilized recruitment fliers and an online survey platform that had both English and Spanish versions. In this case it is important to also share your findings in both Spanish and English to ensure consistency and access for all participants.

Partnerships

Are there community organizations or others with whom I am working that can help disseminate the results?

A. Leveraging existing partnerships can help amplify your reach.
B. Community partners can help ensure findings are communicated in a clear and contextually appropriate way.[6]
C. Study examples:
    a. You are studying the impacts of having a family member with a serious chronic illness on teenagers. Teens are recruited from a local high school. Consider working with school leadership to present findings not only at the local school but others throughout your district. Presentations for PTAs, school boards, and teacher conferences can be good places to reach important stakeholders in the community.
    b. You are studying the impact of an app to increase daily step counts among older adults. In addition to sending a letter to the individuals who signed up for your study, you partner with local senior centers to hang

fliers, and the Penn Memory Center to highlight your findings in their monthly newsletter with 8000 subscribers.

Sensitive findings

Should results be shared publicly or only with specific groups?

A. Make sure to follow consent procedures when disseminating sensitive findings.
B. Disseminate findings in an accurate, unbiased, and transparent manner.
C. Consider partnering with public health organizations that have the potential to reduce harm or stigmatize individuals or communities.[6]
D. Study example:
    a. You are studying the effects of a new drug on patients who are HIV positive. You publish the results in an institutional newsletter and send the link to all patients from that institution.

Dissemination Tools & Approaches

Audiences may have different preferences for receiving information. Many tools and approaches are complimentary and can be combined in different ways. For example, an infographic might be included in a mailed letter or an email, included as an exhibit in a manuscript, added to a study website or slide deck for a presentation, or even posted on its own in a post on social media. Consider these tools and approaches when writing your dissemination plan and find examples in Appendix D:

Mailed letters

A. Include key findings, infographics, and where to find more information
B. A QR code can be useful for linking to web-based resources
C. See template in Appendix D (p. 30)

Email

A. Include key findings, links to articles, and relevant infographics
B. See template in Appendix D (p.30)

Infographics

A. Modify exhibits used for academic dissemination into a visual with plain language
B. Use platforms like Canva, PowerPoint, or Adobe Express (Penn employees have free access to Adobe Pro) to create easy-to-understand graphics

Interactive sessions

A. These can be held in person or virtually
B. Provides participants and community members the opportunity to interact with study personnel
C. Consider partnerships with community groups or hosting Q&As
D. Consider providing handouts or copies of other dissemination materials so that attendees have something to refer back to
E. This can include conferences for professional stakeholders

Websites

A. Host results on a project website for easy access and sharing
B. Include downloadable resources and FAQs

Comics

A. Use narrative storytelling to present findings in an engaging, visual format
B. Consider collaborating with artists or graphic designers

Videos

A. Narrated PowerPoint presentations or short animated videos explaining key findings
B. Consider whether you require outside contractors to develop a video for you

Social media

A. May be particularly useful for younger or general audiences, but not necessarily geriatric populations
B. Consider partnering with moderators of web-based community groups to post an infographic and/or links to publications
C. Tools like Canva have templates for social media posts

Manuscripts

A. Peer-reviewed publications remain the gold standard for academic dissemination
B. Include a lay summary in publications, when possible, to make results accessible to non-academic audiences

Newsletters

A. Print or web-based distribution
B. Consider partnering with centers within the Penn or larger community to reach populations relevant to your research

Ads

A. Paid advertisements may be used to reach target audiences
B. Examples include: sponsored social media posts, radio ads, and printed ads

Patient portals

A. Electronic health record-based patient portals (e.g., myChart) and other web-based portals (e.g., Way To Health) can be useful tools for communicating information
B. If you are already engaging with participants through one of these platforms, sharing results there may make the most sense

Media/news outlets

A. Results may be shared with the public with or without your involvement
B. Penn has resources to help you boost your message:
    a. Leonard Davis Institute offers a fee course, Translating Research for Impact, which includes information about talking to the media
    b. Penn Medicine's Communications Department provides guidance for engaging with both external media and promotion through University Channels. If the press reaches out to you, they advise reaching out to the Communications Department for guidance prior to responding.

Writing a Dissemination Plan

Your team is ready to develop a dissemination plan. Ideally, you will think about this before you start the project, ensuring to include any costs in your budget when preparing your grant proposal. But do not worry if you did not plan early, as you can create a dissemination plan at any time! Sit down with your team and answer the questions below and then write down your dissemination plan.

Key components of a dissemination plan

When developing a dissemination plan, think back to the 5 Ws (and 1 H) you probably learned about in grade school: Who, What, Where, Why, When, and How. You can find additional guidance about building a dissemination plan in the resources section. When creating a dissemination plan, you will want to define:

Who

Ask yourself: who is our audience?

A. Identify the stakeholders you are trying to reach and who will receive the results
B. Tailor language and format to fit the needs of each stakeholder group

Ask yourself: who is responsible for the dissemination plan?

A. Identify who will develop your dissemination plan, create the materials, and be responsible for distribution
B. Determine whether your existing team will work alone or alongside internal or external partners

What

Ask yourself: what are the messages we want to share?

A. The messages may be the same for each stakeholder group, but the wording will need to change

Where

Ask yourself: what are the appropriate venues to disseminate your messages?

A. In person or virtual
B. Synchronous or asynchronous

C. Think about specific locations, events, or platforms that make sense for your audience

Why

Ask yourself: what is the purpose of dissemination for our project?

A. Examples of purpose are:
    a. Raising awareness among your audience
    b. Informing or educating your audience
    c. Engaging your audience
    d. Promoting results to your audience

When

Ask yourself: what timeline makes sense for our project?

A. Determine when and how often results will be shared
B. Identify a clear beginning and end for dissemination
C. Decide if you will be evaluating your dissemination efforts

How

Ask yourself: What tools, methods, and approaches make sense for disseminating your messages?

B. See our list of potential tools, methods, and approaches in the section on Dissemination Tools & Approaches, and examples in Appendix D.

Dissemination planning: Stakeholder analysis

You can use the headers and questions above to create a stakeholder analysis. A stakeholder analysis doesn't have to be limited to your participant and community stakeholders – you can include everyone! Below we provide a template for writing down your stakeholder analysis and an example of a completed template.

Template

WHO	WHO	WHAT	WHERE	WHY	WHEN	HOW
Audience	Team members	Messages	Appropriate venues	Purpose	Timeline	Tools and Methods

Study example

In this project, the research team interviewed people with Alzheimer's Disease and Related Dementias (ADRD), their care partners, and health care professionals who work with people who have ADRD about treating these conditions.

WHO	**WHO**	**WHAT**	**WHERE**	**WHY**	**WHEN**	**HOW**
Audience	Team Members	Messages	Appropriate venues	Purpose	Timeline	Tools and methods
Participants	**CRC**^ and **JRP**^^ to write the content **PI**^^^ to review, edit, and distribute	We want to share what we learned from the interview study you were a part of. We learned that people wish treatments for memory problems would reverse symptoms but feel this is not possible. We also learned that slowing down the progression of symptoms is not favorable for many people. Some feel it would prolong suffering for the patient or distress for the care partner.	Virtual; synchronous or asynchronous	Engagement Education	After each manuscript is published, a plain language summary will be sent out with the full manuscript attached.	Plain language summary sent via email to patients and care partners who completed an interview
People with dementia and their families	**CRC** to write **PI** to review and connect with PMC **PMC**^^^^ (Partner Center) to distribute	Talk to your care team about what would make you want to try a new treatment for memory problems. You can also talk to them about what would not make a new treatment worthwhile. This can help them understand what types of treatments they should recommend.	Virtual; asynchronous	Awareness	ASAP after data collection	Plain language article in the PMC's newsletter that is sent via email to patients, family members, and others
Healthcare professionals and dementia researchers	Full study team	Understanding patients' preferences about interventions is important. Incorporate conversations into practice.	Synchronous: conferences, PMC; Asynchronous: publication	Promotion	Ongoing	3 manuscripts 2 oral presentations 1 poster presentation 1 sharing session at PMC weekly meeting

^ CRC: clinical research coordinator
^^ JRP: Joint Research Practices
^^^ PI: principal investigator
^^^^PMC: Penn Memory Center

Additional Considerations for Human Subjects Research Operations

When developing your dissemination plan, include it in your grant proposals, study protocols, and IRB submissions. You can include a short narrative, utilize the stakeholder analysis table, or use another format that works best for your team. Below we include guidance from our discussion with Penn's IRB. If you have additional questions, the JRP is here to help. You can also reach out directly to your IRB administrator or sign up for IRB office hours here.

C. Grant proposals
    a. Include a description of how you plan to share results to participants in the dissemination plans to demonstrate participant-centeredness
D. IRB protocols
    a. The JRP spoke with Penn's IRB to get guidance about any human subjects concerns when sharing results with participants. If you are not working with Penn's IRB, we suggest checking guidance from your local IRB. Here are the Penn IRB's recommendations:
        i. It is encouraged to disseminate study results to participants
        ii. For an initial IRB submission:
            1. Include language about sharing results to participants (see below for example)
            2. Ensure you receive approval to collect the appropriate contact information you need to be able to carry out dissemination plans. Include language in the consent form/process to inform participants that they will receive study results. Try to plan ahead and specify how you will share results and the time horizon for doing so.
        iii. If you are already IRB-approved:
            1. The only instance where your team might run into issues is if the consent explicitly states a discrete timeline in which you will destroy participants' contact information that precedes the dissemination timeline
            2. If you need updated contact information for participants who were/are Penn Medicine patients, and

you think you can obtain this updated contact information via PennChart, then simply submit a modification, as contact information is protected health information (PHI).

b. Example language for consent forms:
    i. "We will share the results of this study with participants through email and a project website. A plain language summary will be available, and participants may request additional information if needed."

Create Accessible & Clear Content

You have your dissemination plan written down, and it is time to start developing your materials. Plain language matters. Communicating research results in plain language makes information more accessible and meaningful to participants. We include a few guidelines below to keep in mind when you are writing dissemination materials. The JRP Plain Language Guide provides more detailed recommendations.

Tips for creating accessible content and clear communication:

A. Cut sentences to **8-10 words**
B. Limit paragraphs to **3-5 paragraphs**
C. Aim for **6th to 8th grade reading level** (for an audience of patients)
D. **Avoid jargon** and technical terms
E. Use **familiar, consistent words** instead
F. **Spell out** acronyms
G. Use **headers, bolding,** and **bullet points** for clarity
H. Use **active voice**
I. **Separate** stacked nouns
J. Use **infographics or visuals** to enhance comprehension

Consider involving study participants, community members, and/or consulting staff with ties to the community when developing dissemination materials to ensure relevance and clarity.[11]

Study example: You have recruited study participants from a nursing home. To engage the community, you form a community advisory board (CAB) composed of the nursing home's residents. The CAB advises you on study procedures. They can help choose the dissemination tools, approaches, and language that are most effective and accessible for participants.

By utilizing plain language tips, complex messages can be communicated effectively.[11]

Plain language examples:

Original Text	Tip	Revised Text
CHW	Spell out acronyms	Community health worker
Double-blind randomized controlled trial Providers, clinicians, or health care staff	Avoid jargon. Instead, use familiar, consistent words	Research Doctors
Why am I having hiccups, an upset stomach, or heartburn? If you are using gum, this is usually because you are chewing the gum too much. Chew the gum less. When you are not chewing, place it between your gums and cheek. If you are using lozenges, this is usually from chewing the lozenge or sucking on them. Make sure you do not chew the lozenge. Place them in your cheek and let them dissolve. If symptoms continue, contact your doctor for other ideas to stop these problems.	Cut sentences to 8-10 words Limit paragraphs to 3-5 sentences Use headers, bolding, and bullet points	**Why am I having hiccups, an upset stomach, or heartburn?** **If you use gum:** This is usually because you are chewing the gum. Chew it only a few times. This will activate it. Then place it between your gums and cheek. Think of it as a wax instead of gum. **If you use lozenges:** You may be sucking on or chewing the lozenge. Place the lozenge in your cheek and let it dissolve.
Reading level: 11.4 The nicotine contained in nicotine gum, lozenges, or patches does not contain the chemicals that cause cancer and other diseases. The goal of NRT is to support your transition away from cigarettes or other tobacco products.	Aim for 6th- to 8th-grade reading level	Reading level: 6.5 Cigarettes can cause cancer and other diseases. Cigarettes contain nicotine. When you use cigarettes, your body gets used to nicotine. Patches, lozenges, and gum, have small amounts of safe nicotine. Patches, lozenges, and gum are also called Nicotine Replacement Therapy (“NRT”). The safe form of nicotine in NRT helps you to quit smoking. With this help, your body will not need nicotine over time.
Consent must be provided	Use active voice	You must click “consent” to join the study.
You are an American Heart Association-funded BETTER Center participant	Separate stacked nouns	You are a participant of the BETTER Center. The BETTER Center is funded by the American Heart Association.

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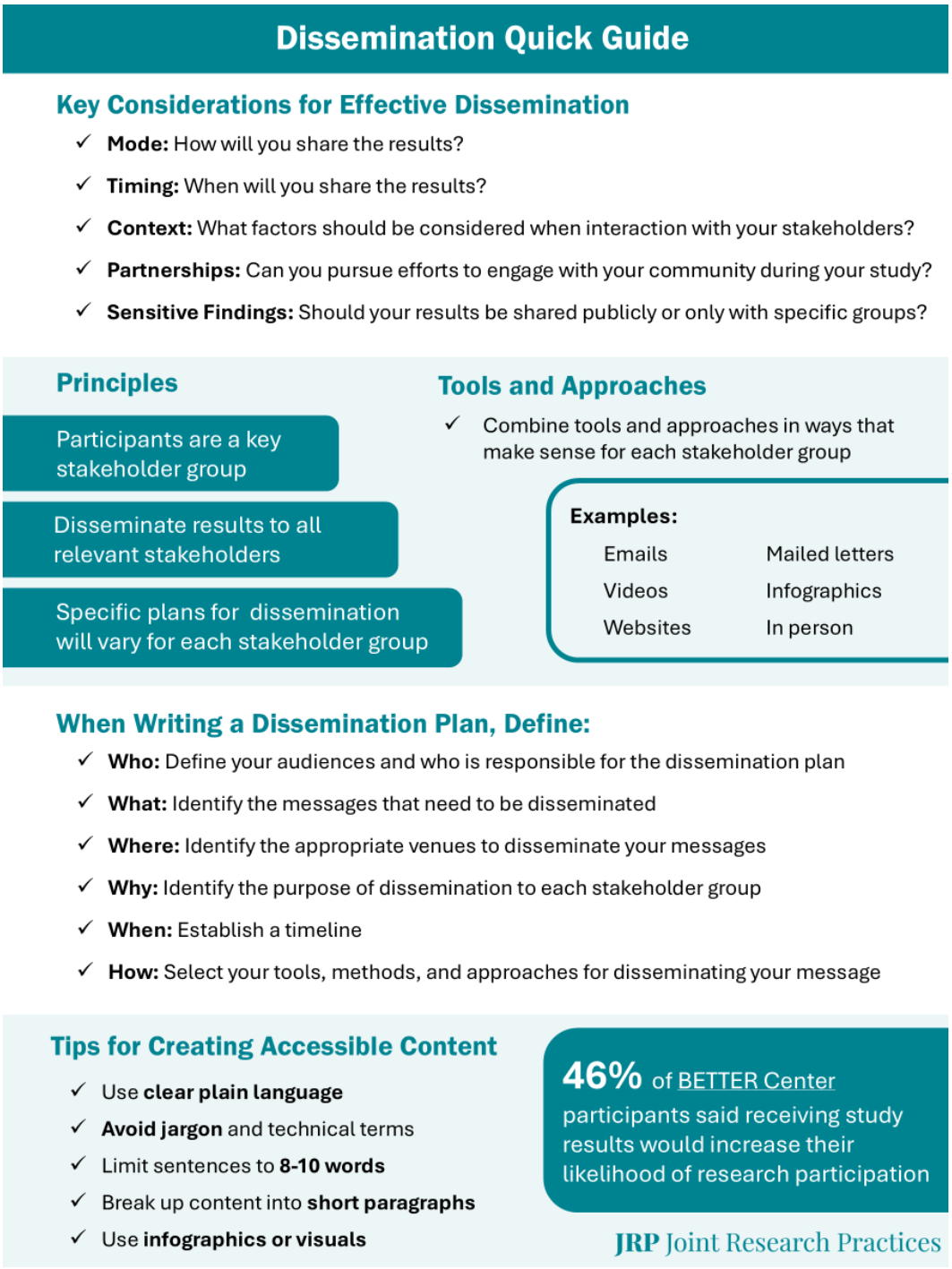
Appendix A: Dissemination Quick Guide



Appendix B: Additional Resources

Ours is not the only guide or toolkit that exists. First and foremost, we have tailored this guide to include examples from and meet the needs of our collaborators at CHIBE and PAIR. See below for additional tools.

The Vanderbilt Institute for Clinical and Translational Research (VICTR) has a list of toolkits available to the public. These toolkits include a variety of dissemination types:

A. Disseminating results to the public
B. Disseminating aggregate research results to participants
C. Disseminating individual research results to participants

Here are links to some of the resources available in selected toolkits:

A. Agency for Healthcare Research and Quality:
    a. Quick-Start guide to dissemination for practice-based research networks
    b. Development of a planning tool to guide dissemination of research results
    c. Publishing and communications guidelines
B. Institute of Education Sciences:
    a. Dissemination plan template
    b. Program evaluation toolkit, module 8: dissemination approaches
C. Virginia Commonwealth University:
    a. Dissemination planning rationale and resources
    b. Dissemination planning template questions for a study team to ask themselves
    c. Dissemination plan examples

Appendix C: FAQs

1. What is the role of research coordinators in disseminating results. How can research coordinators be helpful?

A: This is up to the study team and may vary based on interest, bandwidth, the size of the team, previous study interactions, and the patient population. CRCs can help develop and/or implement the dissemination plan. This might include helping to design the materials or being the person to send out dissemination materials.

2. We did not initially create a dissemination plan for our study; now it is time to share results, and we would like to include participants. How do we go about creating a dissemination plan after data collection?

A: While the earlier the better, you can create a dissemination plan at any time. Using the *Who, What, Where, Why, When, and How* template, take some time at your project meeting to answer these questions. If you get stuck or need help getting started, you can always schedule a PERKS consultation. We have helped multiple research teams disseminate results without a preexisting plan, and the process has been fast and easy.

3. What if the results are negative? How should we frame them for participants?

A: It is important to be honest with your participants. Sharing negative results promotes transparency, and it may be worth explaining to participants that the study is important because it allows other researchers to learn from unsuccessful interventions. It also prevents them from wasting time on similar experiments, and ensure we are not giving patients treatments that cause harm but don't have benefit. This is also where engagement with your participants and community can be beneficial. Consider consulting with a small group to get your messaging right before disseminating to the full group.

4. Dissemination is not a line item in my budget. How do I disseminate with little to no budget?

A: Chances are, dissemination is in your budget – just not this kind of dissemination. Don't worry, you have done most of the heavy lifting already. You can develop and implement a dissemination plan repurposing the information included in your manuscript, slide deck, or poster. Additional line items like printing and mailing, consultants, or room rentals can be avoided. Sending an email to your participants, for example, will not cost you anything other than time and effort.

5. I don't have a graphic designer. What resources are available to me to make my product engaging?

A: You can use resources like PowerPoint or Canva to help with design. If you're having trouble, take inspiration from Appendix D in this report – none of these used professional graphic designers. And if you are still having trouble, schedule a PERKS consultation.

6. Does the IRB support sharing results with participants?

A: We have spoken with the Penn IRB! They support and even encourage sharing results with participants. You can find a summary of the guidance we received in the section on Additional Considerations for Human Subjects Research Operations in this guide.You can also talk to the IRB about your specific project during IRB office hours every Thursday from 10am-12pm. You can sign up for a 15-minute slot here.

Remember, sharing results with participants is included in the Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Participants (articles 6 and 26).

7. Can I share results with participants if I did not explicitly ask their permission to do so ahead of time?

A: Ideally, in the consent and enrollment process, you can make a note of your intention to share results at the conclusion of the study. You can even offer an option to opt-out of that communication if they are not interested. If you have not done that, however, we suggest leaving it up to the study teams to decide if the results may be sensitive to participants. The IRB supports and encourages sharing results with study participants; see Question 6 for IRB considerations.

8. Do I need to disseminate results for retrospective research? How?

A: Disseminating results to people whose health data you used may be unfeasible and even unavailable, at least on an individual basis. This is where university, health system, and community partners would be viable options for reaching the community who might be impacted. For example, working with a center in the Penn Medicine network to include a plain language summary in their patient newsletter.

9. What if I am doing a large prospective study with thousands of patients and a waiver of informed consent?

A: This is another case where disseminating results to people whose health data you used may be unfeasible and even unavailable, at least on an individual basis. This is where university, health system, and community partners would be viable options

for reaching the community who might be impacted. For example, attending a local health fair to share information with the community.

10. What if I am doing a secondary data analysis?

A: This guidance is focused on groups doing primary data collection and analysis. If you are doing secondary data analysis, the data is most likely deidentified, and you do not have a way of accessing participant contact information to share results. You can still aim to reach important community stakeholders. See Question 8 for additional guidance.

Appendix D: Template & Study Examples

This Appendix includes examples of dissemination materials that were shared with participants, community stakeholders, and, in some cases, the general public.

Writing mailed and emailed letters

Letters with summary results, infographics, and links to additional information are likely one of the most accessible ways for your study team to share results with participants. You may already be collecting mailing or email addresses for recruitment or other study activities. This can be a convenient low-touch option for your team.

Include headers in bold with bullet points or a short 1-2 sentence paragraph and an infographic. You will want to include background, results, additional resources, and a thank you for their contribution to the study. Here are some headers to get you started, but we encourage you to adapt them to your project:

- Main takeaway
- What this study looked at
- What we thought might happen
- What the results were
- How you can use this information
- More information (links to media articles, the publication, and/or a blog post with the contents of the letter, contact information for someone who can answer questions, etc.)

You can use the template on the next page as a starting point and/or take inspiration from the examples below.

Dear [Name]:

We are happy to announce that the [insert name] study at the University of Pennsylvania that you were a part of is finished. We want to share with you what we learned.

Main takeaway:
With your help, we learned that …

[Infographic here]

What the study looked at:

What we thought might happen:

What the results were:

How you can use this information:

More information:

- Find the study results published here [hyperlink]
- See media articles in [outlets/article names – hyperlinked]

If you have any questions, please email [name] at [email].

What we learned from the [name of study] was only possible due to your help. Your efforts will help us design better care for patients in the future. Thank you for all your time and effort!

Sincerely,

[Name]

Principal Investigator on behalf of [study team name]

Study Example 1: Tracking Recovery in Acute Injury to the Lungs Study (TRAILS)

Tracking Recovery in Acute Injury to the Lungs Study

TRAILS

June 2022 to March 2024

Dear [Name]:
Thank you for joining our research study in the Palliative and Advanced Illness Research (PAIR) Center! We want to share the results with you.

What were the goals of the study?

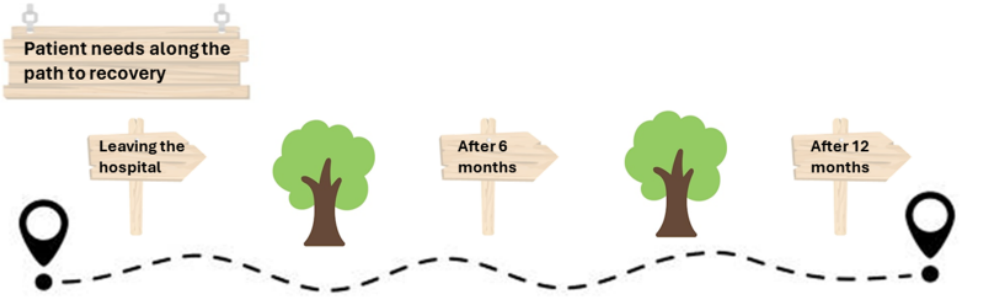
- To understand patients' feelings after being in an intensive care unit (ICU) on a breathing machine
- To understand what helped and did not help patients recover from being in an ICU

How did we do this study?

- We asked you to answer surveys when you left the hospital. Then, we asked you to answer surveys and extra questions about what helped you recover 3, 6, and 12 months later.

What did we learn?

- Dignity, or feeling valued, respected, and like one's real self, is important for patients
- For some patients, dignity got better, some got worse, and some stayed the same
- Dignity may be related to quality of life and disability after being in an ICU



- Getting a packet with important information
- Kind treatment by hospital staff
- Learning about being on a breathing machine
- Knowing what to expect after leaving the hospital

- Help with making appointments
- Follow-up from doctors, nurses, and therapists

- Support groups
- Mental health services

What will we do next?

- Create and test ways to help patients with their recovery after being in an ICU

Where can I find more information?

- See the full study results here: [hyperlink]
- If you have questions, you can email the study team at TRAILS@pennmedicine.upenn.edu
- Here are resources for patients after being in an ICU:
- Post-Intensive Care Syndrome (PICS) information

We are very grateful that you shared your experiences to help us understand dignity and what helped you recover from being in an ICU. This will help us take better care of patients.

Sincerely,
Rachel Kohn, MD, MSCE and Michael Harhay, PhD (study leads), and the entire TRAILS team

Palliative & Advanced Illness Research (PAIR) Center
University of Pennsylvania

Dear Trial Participant,

Thank you for taking the **BETTER Center's Research Preferences Survey last year!** We wanted to share some of what we learned so far.

Main takeaway:
With your help, we learned that it is important to participants to hear updates from us about a study's progress and conclusions.

"[Tell us] the outcome." – *Black rural woman*

"Share results of the study with participants." – *White woman*

"Maintain communication to keep abreast of the study's progress." – *Latina woman*

What the study looked at:
We asked women and people from Black, rural, and Latinx communities their thoughts on participating in research.

What the results were:
People from these groups thought it was important for the study team to share results and outcomes. 46% said getting results would increase likelihood of participating.

How you can use this information:
If you are asked to participate in a study, you can ask how the team will share results.

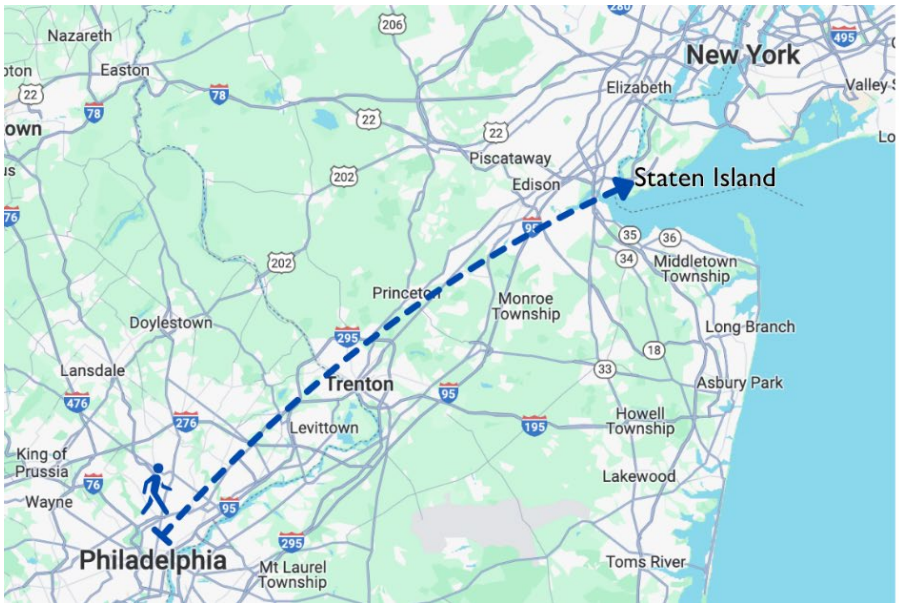
More info:
You can email us if you have questions at Better.Center@pennmedicine.upenn.edu

Thank you so much for contributing to this research!

Dear [Name]:

We are happy to announce that the STEP 4Life study at the University of Pennsylvania that you were a part of is finished, and we wanted to share with you what we learned.

Main takeaway:
With your help, we learned that people at risk for Alzheimer's disease who played a simple game with a support partner increased their walking and physical activity.



The game and support led people to walk an **extra 1,700 steps per day** or around 70+ miles over the intervention period — **equivalent to walking the distance between Philly to Staten Island, New York, over 3 months.**

What the study looked at:
We know that people who move and exercise more have a lower risk of mental decline, but most people don't do enough physical activity. We wanted to test whether feedback, a game, and support from a partner could help people who are at risk for Alzheimer's disease or related dementias move more.

What we thought might happen:
We thought that people in the study who played a game and had support from a partner would have more physical activity during the 12-week period and that this would continue during the 3-week follow-up period.

What the results were:
People who played the game with a support partner had greater change in their daily step count than the control group by about 1,700 steps per day, and this trend continued for several weeks after the game was stopped (the difference was about 1,200 steps per day in that period).

Also, we learned that people who were at higher genetic risk (due to having the APOE4 genotype) were **not** more active than people who were at average risk (did not have APOE4 genotype).

Interestingly, we also found that people who felt their risk for Alzheimer's was higher were more active than those who felt their risk was lower.

How you can use this information:
Staying physically active is helpful to maximize your independence and stay healthy as you age. Applying strategies to make exercise more fun by making it into a game or to make it more social by having a support partner can be helpful ways to stay active over time.

More info:
Find the published results **here**. If you have any questions, please email Dr. Greysen at ryan.greysen@pennmedicine.upenn.edu.

What we learned from the STEP 4Life study was only possible due to your generous contributions of time and effort. Your efforts will help us design better care for patients in the future. Thank you for all your help!

Sincerely,

Ryan Greysen, MD

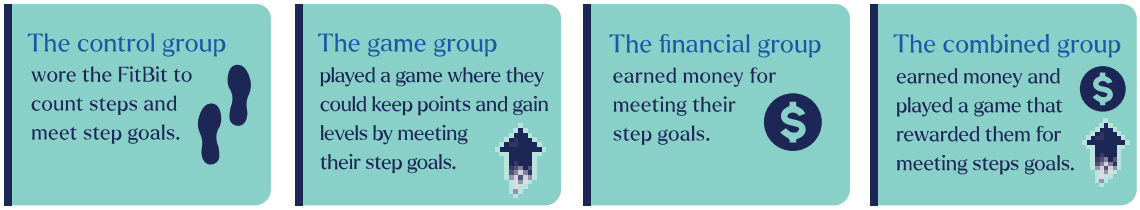
Principal Investigator on behalf of The STEP 4Life Study Team

Penn Medicine

Study Example 4: BE ACTIVE

Dear Participant's Name:
We are happy to announce that the BE ACTIVE study at the University of Pennsylvania that you were a part of is finished. We wanted to share with you what we learned from the study.

Study goal:
We know that people who do more physical activity have a lower risk of serious heart problems, but most people don't walk enough. We wanted to test different ways to increase walking for people who had a serious heart problem in the past. Everyone in the study received a FitBit watch to count steps and then was randomly placed into 1 of 4 groups:



What we thought might happen:
We predicted that people in the game group, the financial group, or the combined group would do better hitting their step goals compared to the control group.

What the results were:
The results of the study confirmed our prediction. The combined group did the best at hitting step goals during the 12-month study. The combined group also continued to walk more during the 6-month follow-up period. The game and financial groups also walked more than the control group, but less than the combined group.

Key takeaways:
The results suggest games and financial incentives can help increase walking for people with heart conditions. Using games and money to increase walking has the potential to help improve the heart health of patients in the future.

News articles:
The Washington Post: Incentives — including cash — helped people raise their step counts
The Today Show: New study shows daily incentives help you reach exercise goals

If you have any questions, please email samantha.coratti@pennmedicine.upenn.edu.

What we learned from the BE ACTIVE study was only possible due to your generous contributions of time and effort. Your efforts will help us design better care for patients in the future.

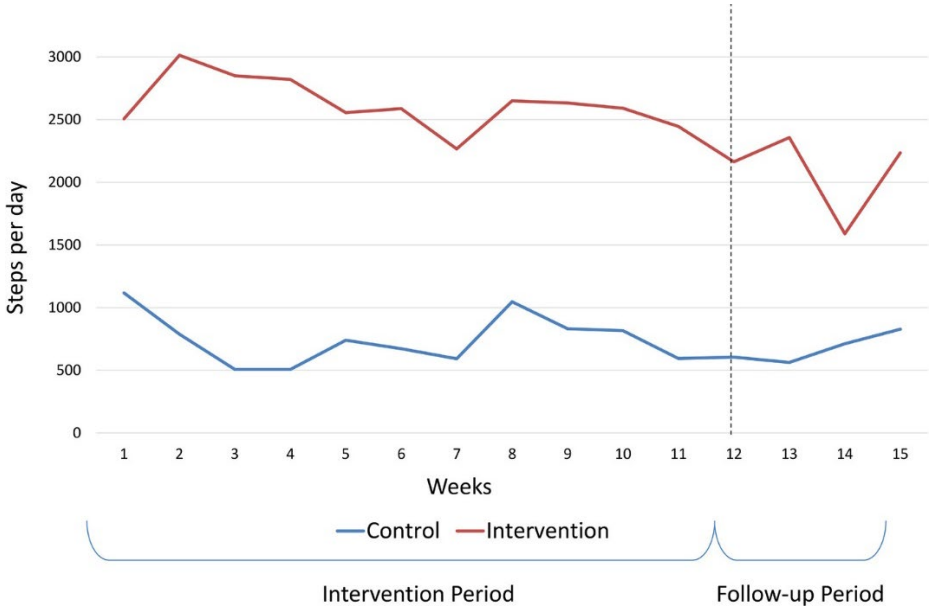
Sincerely,
Alexander C. Fanaroff, MD, MHS, Principal Investigator

Penn Medicine

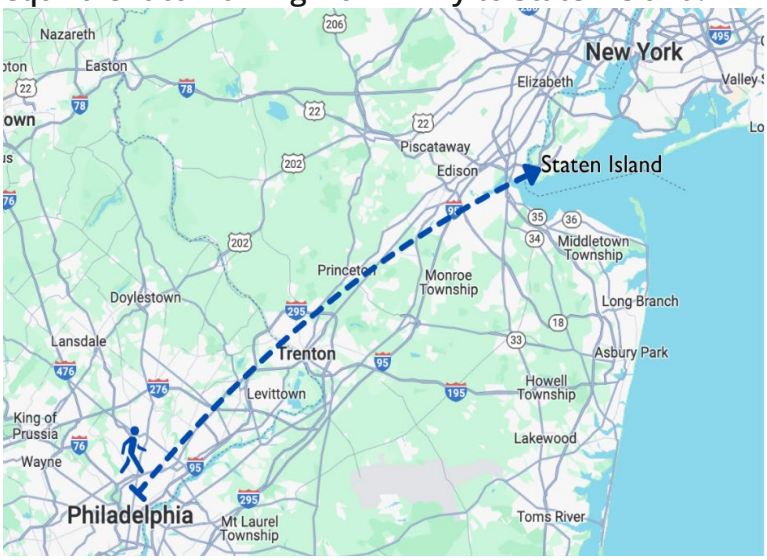
Transforming academic exhibits into plain language infographics

Study Example 1(quantitative): STEP 4Life

We took a line graph from the paper Dr. Greysen and his team published in Alzheimer's & Dementia showing how many more steps people took when they played a game with a support partner…



…and turned it into an infographic that showed their increased step count was equivalent to walking from Philly to Staten Island:



The game and support led people to walk an **extra 1,700 steps per day** or around 70+ miles over the intervention period — **equivalent to walking the distance between Philly to Staten Island, New York, over 3 months.**

Study Example 2 (qualitative): I-MEASURED

We took this thematic quote table from one of Dr. Katie Auriemma's I-MEASURED manuscripts discussing patient and caregiver perspectives on delaying dementia progression…

Table. Themes and Representative Quotations[a]

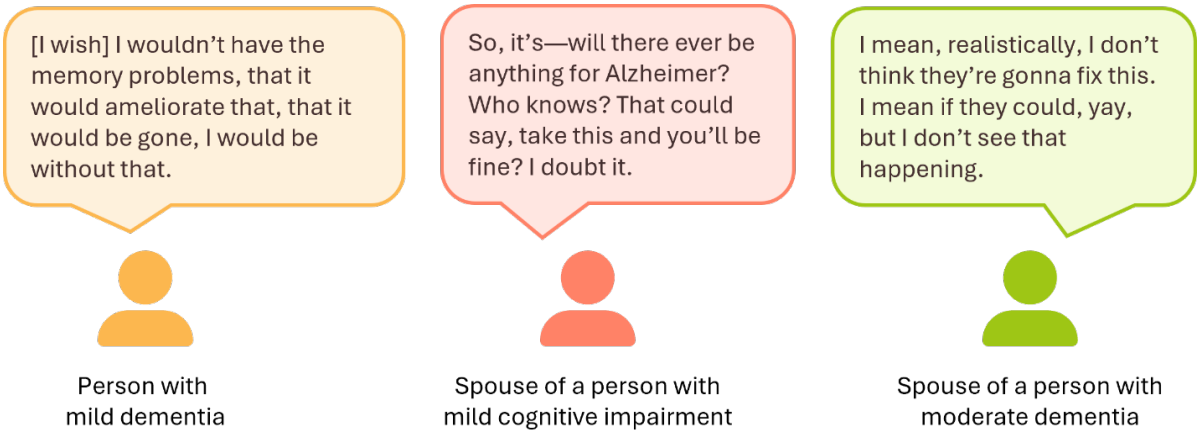
Theme	Representative quotes	Participant
Participants wish that dementia therapies could be curative, but believe that to be currently unrealistic	I wish there was something that we could do to even end it or make it better or reverse it or something, but there's nothing really right now that's available that will do that.	Care partner, spouse of person with moderate dementia
	[I wish] I wouldn't have the memory problems, that it would ameliorate that, that it would be gone, I would be without that.	Person with mild dementia
	Being able to prevent, because you're sure not gonna rebuild what's lost.	Person with mild dementia
	So, it's—will there ever be anything for Alzheimer? Who knows? That could say, take this and you'll be fine? I doubt it.	Care partner, spouse of person with MCI
	I mean, realistically, I don't think they're gonna fix this. I mean if they could, yay, but I don't see that happening.	Care partner, spouse of person with moderate dementia
Slowing or halting cognitive decline is desirable primarily for persons with mild stage disease	Well, if I could see that I was plateauing out, it would be wonderful.	Person with MCI
	But if it could stop the progression and allow her to continually live and age in place at this level before it gets too far along.	Care partner, child of person with mild dementia
	Stabilizing where he is right now, stopping progression. That would probably be the biggest gift.	Care partner, spouse of person with mild dementia
	You know, when I think back to where we were 2 years ago, if we could have even just halted it there, that would have been lovely. So I would say anything that would halt progression would be amazing. Anything that, obviously, could turn it around would be even more amazing, but that seems a lot to ask of a drug.	Care partner, child of person with moderate dementia
Slowing disease progression is undesirable for some, and may be perceived as harmful	Well, I hate to be Debbie Downer, but if it would keep him the same as what he is, I wouldn't let him have it…If it's not gonna change you and make you better and back to how you were before you had it, then it's wasted on him.	Care partner, spouse of person with moderate dementia
	If you would have asked me this 2 years ago, I would have said just stop it at that point. You know, you don't have to bring all his memories back because you can—you could make new ones at that point. But today I don't think there's any there, so today if it happened, I would want it to be able to reverse it.	Care partner, spouse of person with severe dementia
	Well, pie in the sky. Reverse it. Ain't gonna happen ever. Well, if there's something that could—do I even wanna slow it down? That's such a hard question. Do I want to?…I don't know.	Care partner, spouse of person with mild dementia
	I'm almost getting to a point—this is gonna sound really cruel and mean, but if we're going at the pace we're going in another year. I don't know that I want it to get better. How long are we gonna drag this out? I mean, I don't know how long I could do it.	Care partner, spouse of a patient with moderate dementia

Abbreviation: MCI, mild cognitive impairment.

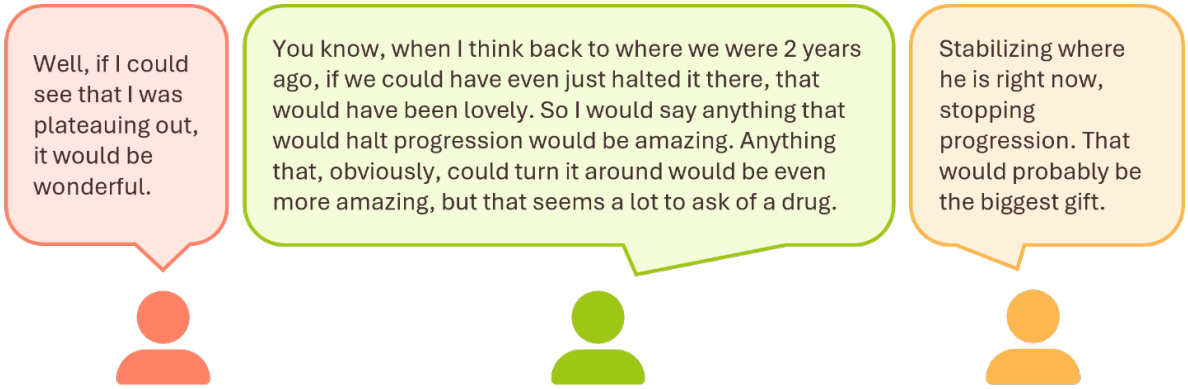
[a] Dementia severity was defined using the following thresholds: Montreal Cognitive Assessment (MoCA): MCI, >25; mild, 18-25; moderate, 10-17; severe, <10; MoCA-Blind: MCI, >18; mild, 13-18; moderate, 7-12; severe, <7; mini-mental status examination: MCI, >25; mild, 20-25; moderate, 12-19; severe, <12; Function Rating Scale: mild, <19; moderate, 19-36; severe, >36.

…and turned it into three illustrative panels with themes written in plain language:

Theme 1: Patients and their families wish that new treatments could cure memory problems, but these hopes often felt unrealistic.



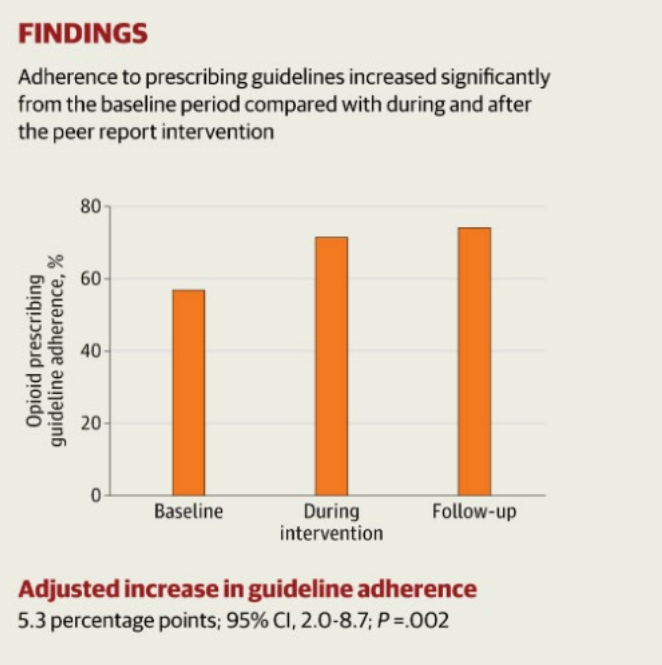
Theme 2: Some patients and their families would find it helpful if a new treatment could slow down or stop the worsening of memory problems.



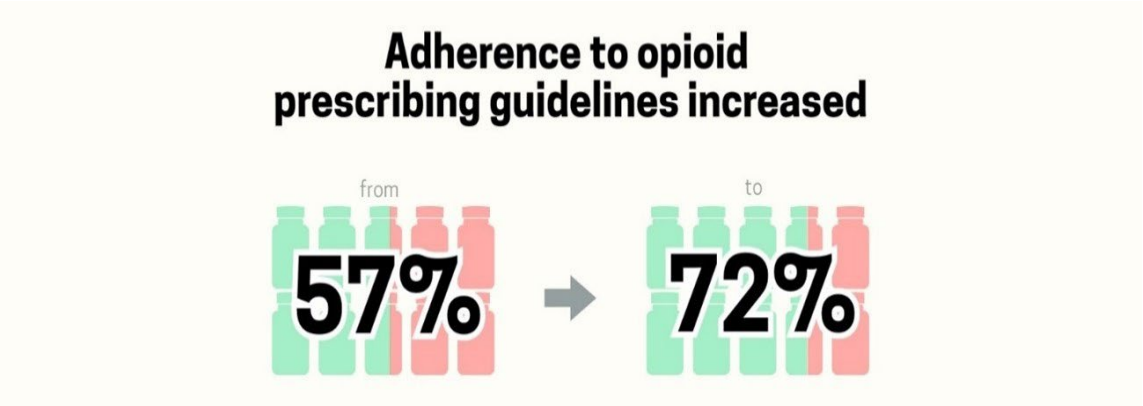
Theme 3: But, some families worried about slowing down or stopping the worsening of their loved ones' memory problems. They felt this could extend their loved one's suffering or cause distress for family members.

Study Example 3 (quantitative): Opioid-Prescribing Study

Drs. Anish Agarwal and Kit Delgado published a paper in JAMA Surgery about post-surgical prescribing guidelines. We took a bar graph from their manuscript showing adherence to opioid-prescribing guidelines when doctors received feedback…



…and turned it into an infographic using pill bottles and large numbers to visually highlight how much the intervention helped improve adherence:



Opportunities to hear results (live) from the study team and ask questions

Sessions where participants and the community have an opportunity to interact with the study team can happen in person or virtually. They can be formal presentations, panel discussions, or Q&A sessions. Be prepared with visuals like slide decks or handouts. These can be used during the session and provided as reference materials for the future.

Study Examples

- The Philadelphia School Health Profiles study team created slide decks and information sheets for their Philadelphia School District administrator partner. She presented survey results to PTAs at high schools across the city.
- Results about an evidence-based clinical intervention project for patients with serious respiratory illness were shared with clinical teams and hospital leadership.

Websites

If you are going to engage with study participants over time, you might consider creating a simple webpage where they can see the project's progress. This could be added to your study's page on a center website or incorporated into other platforms.

Study Example: QHARP Cohort

- This webpage was created with the Dashboard function in REDCap. Here participants can find information about how many people have enrolled, reminders about when they can expect to hear from the study team, and links to other helpful information. When the study team is ready to share results, they will have the option to utilize this platform for dissemination.

QHARP

Developing Quality-Weighted Hospital-Free Days as a Novel, Patient-Centered Outcome Measure for Patients with Acute Respiratory Failure

Thank you again for being part of the study! We currently have **99** patients enrolled. **50** participants have completed their Day 0 (ICU Discharge) survey.

Resources for Participants

Recovering from critical illness or acute respiratory failure is challenging. If you need additional mental health or emotional support, these resources may be helpful: Resources for Mental Health & Emotional Support

ClinCard Frequently Asked Questions (FAQs)

Survey Delivery Schedule

- first survey is delivered right after ICU discharge
- weekly for 5 weeks
- every 2 weeks for 8 weeks
- monthly for 3 months
- every 3 months for the rest of your time in the study

Year 1															
Timing	At ICU discharge	Weekly x 5 weeks					Every 2 weeks x 8 weeks				Monthly x 3 months			Every 3 months	
Survey #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Days since ICU discharge	0	7	14	21	28	35	49	63	77	91	122	153	184	274	364

Year 2				
Timing	Every 3 months			
Survey #	16	17	18	19
Days since ICU discharge	454	544	634	724

Contact Our Team

QHARPstudy@pennmedicine.upenn.edu

(215) 573-2893 (leave a voicemail and we will return your call)

Media

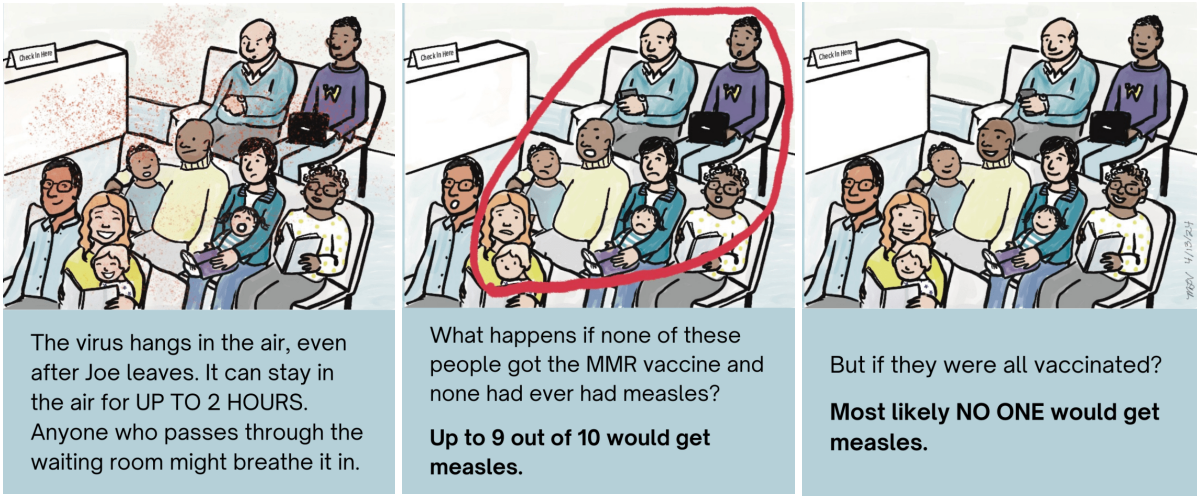
Here, we explore how you can utilize different types of media and media outlets to share your results.

Comics

Comics tell a story, making it easier for your audience to contextualize the message you want to share.

- You can print or publish your comic online
- Find an archive of comics from the public health department of Seattle and King counties here.

Example



Videos

Utilizing the professionals: There are companies that will create short, animated videos to explain your study and results. Below are two examples of animations from the company Paupanimation. The cost is $1,500-$2,500, so this is something you would want to budget for in your grant proposals. You can learn about their process here.

Study Example

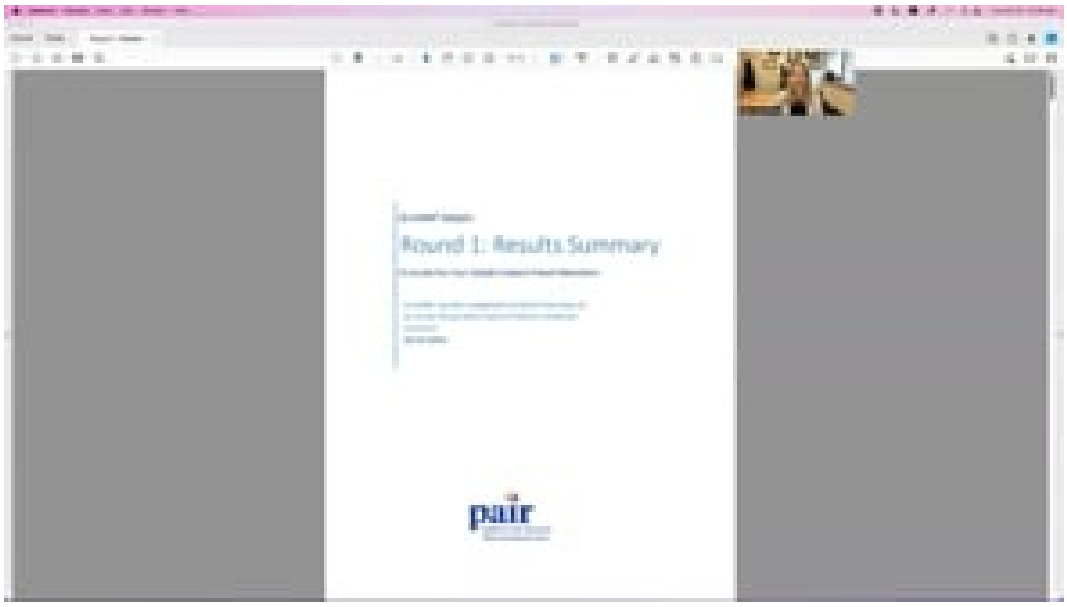
- The B-OK study team developed an animated video focused on the effectiveness of treatment adherence support (TAS) and the benefits of antiretroviral therapy (ART) for individuals living with HIV. The video focused particularly on the concepts of treatment as prevention and Undetectable=Untransmittable (U=U), for which substantial knowledge gaps persist. The video described how we used mixed methods to

evaluate a straightforward visual and tactile tool, the B-OK Bottles ("B-OK"), that incorporated human-centered design and behavioral economics principles and was designed to change and strengthen mental models about HIV disease progression and transmission.

Utilizing your study team: Another option is creating a slide deck, report, or other visual and recording yourself explaining the study results.

Study Example

- The Q-HARP Delphi study team created a series of slide decks and reports that were narrated by study PI, Dr. Katie Auriemma, to recruit Delphi members, introduce them to the study, **share results** after each round's survey, and explain complex concepts. You can find the video where they shared a round 1 results summary here or watch below.



News Outlets

There are resources at PennMedicine and The Perelman School of Medicine that are available to assist with media requests and questions (You can find links to these resources under “media/news outlets” on p.14 in the Dissemination Tools & Approaches section of this guide.) If you aren’t affiliated with Penn, we suggest reaching out to your institution’s communications department for assistance.

Earned media is another way to share study results, as are press releases and interviews. Earned media is public exposure through word of mouth, customer reviews, social media mentions, or media coverage resulting from your content or services’ quality and relevancy.

Study Example

- The Today Show reported on the BE ACTIVE Study that focused on increasing daily step counts for individuals at risk for cardiovascular disease. Click here to find the video on YouTube or watch below.

Social Media

Social media can be a place to share visual abstracts, infographics, summaries, and videos explaining your results. You can also purchase targeted ads, connect with support groups to share your message, or use pop culture references to connect with your audience.

Study Example

1

2

3

4