



Inspiration Catalogue for **Public and User** **Involvement** in Danish **Diabetes and Endocrine** **Academy Activities**



**Danish Diabetes and
Endocrine Academy**

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About the Danish Diabetes and Endocrine Academy

The Danish Diabetes and Endocrine Academy's (DDEA) vision is to promote world-class research to improve the prevention and treatment of diabetes and endocrine diseases. DDEA enhances the quality of diabetes, metabolic, and classical endocrine research by fostering early-career research talent within these fields. We offer activities across four key areas:

1. Education and talent development
2. Networking and collaboration
3. Grants
4. Communication

Our Commitment to Public Involvement and Outreach

Ultimately, DDEA research outcomes should improve the lives of people with diabetes and endocrine conditions. To foster collaboration and mutual benefit between the Academy, our affiliated researchers, and the public, 'Public Involvement and Outreach' is one of DDEA's strategic themes.

Public involvement involves incorporating the perspectives and experiences of people with diabetes and endocrine conditions, their relatives, non-governmental organisations (NGOs) and the broader public into our education, networking, grants, and communication efforts. We aim to ensure that these activities are responsive, timely, and meaningful to those we serve.

Public and User Involvement Explained

In this catalogue, the term "**Public and User**" refers to:

- People with or at risk of diabetes or endocrine diseases and their relatives.
- Members of the public or NGOs interested in the fields of diabetes, metabolism, and classical endocrinology.

"**Public and User Involvement**" refers to the DDEA Secretariat's commitment to considering the ideas and feedback from the public and users when developing strategies for engaging with society through the Academy's activities within education, networking, grants, and communication.

Catalogue Purpose and Plan

To increase the quality, relevance, and value of public and user involvement (PUI) in DDEA activities, we invited 30 researchers, users, and NGOs to participate in the workshop '[Public and User Involvement in DDEA Activities: Education, Networking, Communication & Grants – Why, How, and When](#)', held on 10th and 11th of May, 2023. The workshop's objective was to develop this inspiration catalogue with ideas on how to integrate PUI into DDEA's work.

This inspiration catalogue is the first step towards establishing an environment that supports successful PUI within the Academy. It will be presented to the DDEA's boards, committees, and secretariat. Moreover, it will provide inspiration for developing DDEA's Public Involvement and Outreach Programme and as a consultative document in the strategic planning of DDEA activities.

Importantly, the catalogue is designed to inspire our engagement with PUI, offering a range of possibilities rather than prescribing mandatory actions for the Academy. The nature and degree of PUI engagement will be adapted to fit each specific initiative, guided by strategic considerations of 'why' involvement is necessary, 'how' it can be effectively implemented, and 'when' it is most beneficial to engage the public and users.

The catalogue, presented on the next eight pages, explores the integration of PUI across DDEA's four key areas: education, networking, funding, and communication.

In Brief: Purpose of this Catalogue

This catalogue compiles ideas and insights from the DDEA workshop to enhance PUI across DDEA's initiatives.

PUI is relevant in many DDEA activities. The character of PUI will vary based on the specific activity, type, and level of engagement, guided by strategic considerations of "why", "how", and "when" to involve the public and users in DDEA activities.

General Considerations for PUI in DDEA Activities

General ideas and considerations noted by the workshop participants are listed below. DDEA is encouraged to:

Establish a Strong Foundation: Clearly define the meaning and benefits of PUI, use respectful language, and ensure aligned expectations.

Align Purpose and Develop Strategy: Ensure alignment in purpose and approach among all stakeholders. Develop a clear and comprehensive PUI strategy for DDEA, including a mission statement outlining the commitment to enhancing PUI across the organisation's activities.

Identify Key Stakeholders: Identify the key individuals and groups for involvement in PUI processes.

Develop a PUI Strategy: Formulate a PUI strategy, potentially emphasising the interconnection between biological, psychological, and socio-environmental factors throughout DDEA's offerings, addressing health inequalities, and using non-traditional research communication channels.

Motivate Participation: Motivate users through community building, financial incentives, a visible impact resulting from their input, and by inviting them to engagement activities such as talks, meet-up events, exhibitions, museums, and conferences.

Standardise Payment and Set Clear Expectations: Promote inclusivity by offering a standard compensation for PUI involvement and by defining clear expectations. Establish transparent frameworks for compensation.

Embrace Adaptability and Simplify Engagement: Be open to organisational changes that facilitate PUI. Simplify the PUI process for users and DDEA staff to ensure sustained collaboration and streamline user involvement. Ensure that PUI remains an ongoing effort.

Designate a PUI Champion: Appoint a dedicated PUI “champion” or create a support role within the organisation to lead and coordinate PUI initiatives, ensuring effective implementation and accountability.

Identify Underserved Users: Partner with NGOs, conduct focus groups, and establish an Advisory Board to identify unreached users.

Encourage Diversity in PUI: Promote diversity in PUI by reaching out to frequently underrepresented groups.

Foster Equal Partnerships: Treat users as equal partners throughout all phases of projects, granting them responsibilities and ownership rather than simply seeking input.

Ensure Mutual Benefits: Foster a mutually beneficial relationship that creates value for all parties involved.

Include Users in a Steering Committee: Establish a steering committee that includes user representatives, recruited from relevant sources, to provide input and guidance on DDEA activities. Ensure inclusiveness in the organisation's approach.

Promote User Representation in Decision-Making: Encourage user representation in DDEA's decision-making groups, including the Board, to incorporate their perspectives into organisational decisions and ensure their ongoing influence in decision-making processes.

Address Power Dynamics: Be mindful of potential inequalities in power dynamics and resource allocation, and take proactive steps to address these issues and maintain fairness.

Balance Internal and External Factors: When implementing PUI, ensure a cohesive approach that aligns the organisation's internal dynamics with its external actions, recognising the importance of both aspects.

Customise Public Involvement: Adjust the level and type of public involvement to the specific DDEA activity. Adjust by asking 'why', 'how', and 'when' to involve the public.

Consider Mandatory PUI: Contemplate the possibility of making PUI mandatory for reasons such as politics, ethics, finance, or practicality.

Build a Supportive PUI Infrastructure: Develop a robust PUI infrastructure with tools and training to empower the public and users to participate effectively.

Show Willingness to Engage: Demonstrate a genuine commitment to engage and collaborate with the public and users, allocating necessary resources to support these efforts.

Lead by Example: Adhere to PUI standards within DDEA and explore innovative engagement strategies inspired by successful activities that involve users.

Considerations for PUI in Education and Talent Development Activities

Ideas and considerations for DDEA education and talent development activities generated by the workshop participants are listed below. DDEA is encouraged to:

Address Health Inequalities: Address health inequality issues and research bias, and ensure equitable representation in research activities, promoting fairness and inclusivity.

Combat Stigma: Explore topics related to stigma, its manifestations, and strategies to combat it, and involve the public in discussions and awareness-building efforts.

Encourage Clear and Accessible Communication: Highlight the importance of communication skills for researchers interacting with the public and users, advocating for clarity and accessibility in all exchanges.

Define Clear Responsibilities and Compensation: Define clear roles, establish standardised, mandatory compensation for users, and allow for rate increases and reimbursement for travel and meals to facilitate participation. Create a structured framework for PUI in education activities.

Involve the Public: Foster public involvement throughout the entire event process, proactively reaching out to the public.

Implement Multi-Stage Engagement: Encourage public involvement at different phases of the education process—from planning to evaluation—ensuring education initiatives are engaging and tailored to the target audience's needs.

Tailor Engagement Strategies: Customise public involvement approaches to suit the specific type of activity that is being organised, ensuring relevance and effectiveness.

Promote Inclusivity in In-Person Activities: Engage the public in in-person events such as workshops and lectures to allow for direct interaction and feedback, thereby improving the overall event quality.

Organise Informal Gatherings: Create opportunities for casual interaction through informal meetings and science festivals to foster a deeper connection with the public and users.

Adapt the Language: Consider offering some content in Danish (around 10%) and specify the target audience, whether international or Danish, to ensure effective communication.

Collaborate with User Ambassadors: Consider appointing a user ambassador and encouraging researchers to prepare questions for user input, enhancing engagement. Maintain continuity in user groups to ensure consistency in involvement.

Considerations for PUI in Networking and Collaboration Activities

Ideas and considerations for DDEA networking and collaboration activities generated by the workshop participants are listed below. DDEA is encouraged to:

Accept Loss of Control: Be aware that PUI may involve sharing power and relinquishing control. Recognise the potential for inequality or inequity within these networks and seek solutions for these issues.

Actively Engage with Potential Partners: Follow potential partners on social media, attend meetings and conferences, and establish partnerships. Take these connections seriously and offer responsibilities and equal ownership in projects.

Organise DDEA Networking Events: Organise networking events and conferences with clear objectives and offer incentives for participation, such as funding and legitimacy.

Encourage Networking in Informal Settings: Encourage the discovery of common interests and goals in informal settings, without the rigid structures often present in formal networks with specific agendas. Engage in ongoing efforts to maintain informal networks, as they may not have formal meetings scheduled. Ensuring these networks serve a purposeful and meaningful role.

Foster Personal Connections: Foster dialogue and interaction on both social media and in real-life settings. Build personal relationships and maintain equality in collaborations.

Serve as a Networking Hub: Position DDEA as a networking hub by organising events such as "Meet and Greets" during conferences or partnering with hospitals and patient associations. Leverage individuals with existing network contacts to establish new connections.

Improve Care and Recruitment Efforts Through Networking: Use networking activities to improve care for individuals with diabetes or endocrine diseases, focusing on increasing awareness and knowledge. Simplify the recruitment process for public involvement in research through these networks, and diversify the participant population.

Support Partnerships: Encourage collaborations between people with diabetes and endocrine conditions and researchers. Encourage people with diabetes and endocrine conditions to share their experiences and researchers to integrate these insights into their work.

Foster a Safe Networking Environment: Ensure a research environment that supports the development and use of networks. Prioritise safety and trust in relationships. Encourage individuals to be their authentic selves rather than just representatives of their organisations.

Considerations for PUI in Grant Activities

Ideas and considerations for DDEA grant activities generated by the workshop participants are listed below. DDEA is encouraged to:

Allocate Resources: Dedicate budgetary resources and allocate time for PUI initiatives. Offer initial funding specifically designed to foster researcher-PUI relationships.

Clarify PUI Roles: Clearly define responsibilities for PUI members. Include them in advisory boards and funding panels, and encourage them to engage in calls and funding processes.

Emphasise Research Dissemination: Ensure that research results reach users and the public by requiring applicants to outline project impact summaries in Danish. Facilitate the dissemination of these summaries to the public.

Enhance PUI in Research: Encourage early PUI in project development, promote collaboration in creating lay summaries, and recognise PUI as a valuable research topic.

Ensure Equitable Funding Decisions: Specify roles, commitments, and compensation for potential PUI panel members, ensuring that end users have equal decision-making power.

Expand Beyond DDEA: Extend the PUI approach across research areas. Consider establishing national criteria for PUI and conducting reviews on your own process.

Make PUI a Requirement: Incorporate mandatory PUI criteria into the application process for research projects. Highlight the significance of PUI and describe how PUI will be implemented.

Provide PUI Support: Offer resources such as guidelines, tools, and training, and appoint a PUI "champion" to assist researchers during the grant application process.

Considerations for PUI in Communication Activities

Ideas and considerations for DDEA communication activities generated by the workshop participants are listed below. DDEA is encouraged to:

Engage Users in Communication Platforms: Involve users in suggesting and developing different communication platforms. Define clear expectations for PUI in designing and managing online platforms. Use social media polls to evaluate user needs.

Assess Public Involvement Relevance: Evaluate the significance of public involvement in DDEA's communication strategies, considering its objectives to support effective researcher communication and organise events that facilitate interactions between researchers and interested parties.

Create User-Centric Campaigns and Awards: Initiate a communication campaign that allow users to highlight valuable DDEA research activities. Create the Diabetes and Endocrine Public Award to recognise user contributions.

Improve the DDEA Website: Add a dedicated section for the public on the DDEA website.

Include Users in Decision-Making: Engage users in communication decision-making processes by involving them from the beginning and including them in relevant committees. Adjust the governance structure to ensure user representation in the communication team.

Foster an Online Community: Establish an online forum community led by users. Collaborate with online communities to extend reach. Empower the public and users to take control of social media accounts. Formally partner with organisations like the Danish Diabetes Association and consider successful models from platforms like Diabetes UK and diabetes.co.uk.

Use Mainstream and Online Media: Increase awareness through mainstream media like TV and tabloids. Use platforms like LinkedIn and resources like Videnskab.dk for research communication, debates, and dialogues, expanding the reach of DDEA's activities. Facebook should not be used.

Use Plain Language: Use simple words and phrases. Employ readability checks and conduct user testing to ensure materials are accessible. Collaborate with communication experts (e.g., the National Adult Literacy Agency) or PUI contributors who have expertise in communications to refine these materials.

Consider Stakeholders Diversity: Recognise a diverse stakeholder group, including individuals with diabetes and classical endocrine conditions, their families, the public interested in related research, patient organisations, healthcare professionals, researchers, government entities, social media influencers, the Novo Nordisk Foundation, and international groups.