Impact assessment of dissemination techniques on data collection in a large multicenter Healthy Brain Ageing (HeBA) survey

Daniel F. Pilco-Janeta, Philipp Mahlknecht, Myriam De la Cruz-Puebla, Corinne Horlings, Alicia Garrido, Tainá Marquez, Ruxandra Soare, Christoph Theyer, Simon Leiter, Soumyabrata Ghosh, Kavita Rege, Iris Egner, Jón Pol Gales, Sebastian Schade, Andrés Granolles, Fernanda Farfan, Venkata P. Satagopam, Claudia Trenkwalder, Brit Mollenhauer, Rejko Krüger, Werner Poewe, Eduardo Tolosa, María-José Martí

Submitted to: Journal of Medical Internet Research
on: August 22, 2025

Table of Contents

Impact assessment of dissemination techniques on data collection in a large multicenter Healthy Brain Ageing (HeBA) survey

Daniel F. Pilco-Janeta[1] MD, PhD; Philipp Mahlknecht[2] MD, PhD; Myriam De la Cruz-Puebla[1] MD, PhD; Corinne Horlings[2] MD, PhD; Alicia Garrido[3, 4, 1] MD, PhD; Tainá Marquez[5] PhD; Ruxandra Soare[6] MA; Christoph Theyer[2] MD; Simon Leiter[2] MD; Soumyabrata Ghosh[6] PhD; Kavita Rege[6] MSc; Iris Egner[2] PhD; Jón Pol Gales[5] PhD; Sebastian Schade[7] MD; Andrés Granolles[8]; Fernanda Farfan[1] MD; Venkata P. Satagopam[6] PhD; Claudia Trenkwalder[7, 9] MD; Brit Mollenhauer[7, 10] MD; Rejko Krüger[5, 6, 11] MD, PhD; Werner Poewe[2] MD; Eduardo Tolosa[3, 4, 12, 1] MD, PhD; María-José Martí[3, 4, 12, 1] MD, PhD

[1]Parkinson's Disease and Movement Disorders Unit Neurology Service Hospital Clínic de Barcelona Barcelona ES
[2] Department of Neurology Medical University of Innsbruck Innsbruck AT
[3] Institut de Neurociències Universitat de Barcelona Barcelona ES
[4] Centro de Investigación Biomédica en Red sobre Enfermedades Neurodegenerativas (CIBERNED) CB06/05/0018-ISCIII Barcelona ES
[5] Transversal Translational Medicine Luxembourg Institute of Health Strassen LU
[6] Luxembourg Centre for Systems Biomedicine University of Luxembourg Esch-sur-Alzette LU
[7] Paracelsus-Elena-Klinik Kassel DE
[8] Altoclick Digital Marketing Agency Barcelona ES
[9] Department of Neurosurgery University Medical Center Goettingen Goettingen DE
[10] Department of Neurology University Medical Center Goettingen Goettingen DE
[11] Centre Hospitalier de Luxembourg Luxembourg LU
[12] Lab of Parkinson's & Other Movement Disorders Institut d'Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS) Barcelona ES

Corresponding Author:
María-José Martí MD, PhD
Parkinson's Disease and Movement Disorders Unit
Neurology Service
Hospital Clínic de Barcelona
C/ Villarroel 170
Barcelona
ES

Abstract

Background: Innovative approaches are important for the early detection of Parkinson's disease (PD) and include large-scale online surveys on different risk factors in the general population. Effective dissemination contributes to the success of such studies, but little is known about the reach and cost related to different strategies.

Objective: This study aims to characterize and compare the dissemination strategies employed in the multicenter Healthy Brain Ageing (HeBA) study, with particular focus on the effectiveness of digital and traditional media in engaging diverse populations across three European centers.

Methods: Data from the multicenter HeBA study aiming at remotely identifying PD risk factors and prodromal symptoms in a large cohort of middle-aged and older adults at three European study sites (Barcelona, Spain; Luxembourg, Luxembourg; and Innsbruck, Austria) were analyzed. The dissemination strategies were categorized as digital or traditional. Descriptive statistics were used to summarize the dissemination strategies, geographic reach, linguistic adaptation, survey completion levels, how the participants became aware of the survey and costs associated with the dissemination strategies.

Results: The dissemination strategies in the HeBA study followed a mixed approach. While Barcelona (55.7%) and Luxembourg (53.3%) prioritized digital strategies, in Innsbruck, traditional media slightly predominated (52.2%). Digital advertising strategies were the primary source of recruitment in Barcelona (60.8%), flyers or invitation letters in Luxembourg (41.0%), and radio or television reports in Innsbruck (31.6%). Demographic analysis revealed varied distributions of the sex of participants across centers, while consistently showing that both digital and traditional channels predominantly reached the under-65 age group. The global cost per completed survey was lowest in Barcelona (€4.99), followed by Innsbruck (€9.36) and Luxembourg (€17.80).

Conclusions: Digital dissemination proved highly effective in Barcelona, while traditional outreach had greater impact in Luxembourg and Innsbruck. Understanding how participants engage with dissemination channels is important for optimizing recruitment strategies. A balanced mix of digital and traditional dissemination methods is necessary to support successful questionnaire completion. Achieving this balance between reach, engagement and costs facilitates effective recruitment in population-based studies on neurodegenerative diseases like Parkinson's disease, as demonstrated by the HeBA study.

(JMIR Preprints 22/08/2025:80906)
DOI: https://doi.org/10.2196/preprints.80906

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**
Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.
Only make the preprint title and abstract visible.
No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**
Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http
No. Please do not make my accepted manuscript PDF available to anyone. I understand that if I later pay to participate in <a href="https:/

Original Manuscript

Impact assessment of dissemination techniques on data collection in a large multicenter Healthy Brain Ageing (HeBA) survey.

Daniel F. Pilco-Janeta, MD, PhD,[1] Philipp Mahlknecht, MD, PhD,[6] Myriam De la Cruz-Puebla, MD, PhD,[1] Corinne Horlings, MD, PhD,[6] Alicia Garrido, MD, PhD,[1,3,4] Tainá Marquez, PhD,[8] Ruxandra Soare, MA,[7] Christoph Theyer, MD,[6] Simon Leiter, MD,[6] Soumyabrata Ghosh, PhD,[7] Kavita Rege, MSc, [7] Iris Egner, PhD,[6] Jón Pol Gales, PhD,[8] Sebastian Schade, MD,[10] Andrés Granolles,[5] Fernanda Farfan, MD,[1] Venkata P. Satagopam, PhD,[7] Claudia Trenkwalder, MD,[10, 11] Brit Mollenhauer, MD,[10, 12] Rejko Krüger, MD,[7,8,9] Werner Poewe, MD,[6] Eduardo Tolosa, MD, PhD,[1,2,3,4] and María-José Martí, MD, PhD,[1,2,3,4] & on behalf of the HeBA consortium

[1] *Parkinson's Disease and Movement Disorders Unit, Neurology Service, Hospital Clínic de Barcelona, Barcelona, Spain.*

[2] *Lab of Parkinson's & Other Movement Disorders, Institut d'Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS), Barcelona, Spain.*

[3] *Institut de Neurociències, Universitat de Barcelona, Barcelona, Spain.*

[4] *Centro de Investigación Biomédica en Red sobre Enfermedades Neurodegenerativas (CIBERNED) CB06/05/0018-ISCIII; Barcelona, Spain.*

[5] *Altoclick Digital Marketing Agency, Barcelona, Spain*

[6] *Medical University of Innsbruck, Department of Neurology, Innsbruck, Innsbruck, Austria*

[7] *University of Luxembourg, Luxembourg Centre for Systems Biomedicine, Esch-sur-Alzette, Luxembourg*

[8] *Luxembourg Institute of Health, Transversal Translational Medicine, Strassen, Luxembourg*

[9] *Centre Hospitalier de Luxembourg, Luxembourg*

[10] *Paracelsus-Elena-Klinik Kassel, Kassel, Germany*

[11] *Department of Neurosurgery, University Medical Center Goettingen, Goettingen, Germany*

[12] *Department of Neurology, University Medical Center Goettingen, Goettingen, Germany*

Correspondence to:

Dr. Maria Jose Martí
Hospital Clínic de Barcelona
C/ Villarroel 170, 08036 Barcelona, Spain
Phone: 932278357 / 646 699 750
Mail: MJMARTI@clinic.cat

ABSTRACT

Background: Innovative approaches are important for the early detection of Parkinson's disease (PD) and include large-scale online surveys on different risk factors in the general population. Effective dissemination contributes to the success of such studies, but little is known about the reach and cost related to different strategies.

Objective: This study aims to characterize and compare the dissemination strategies employed in the multicenter Healthy Brain Ageing (HeBA) study, with particular focus on the effectiveness of digital and traditional media in engaging diverse populations across three European centers.

Methods: Data from the multicenter HeBA study aiming at remotely identifying PD risk factors and prodromal symptoms in a large cohort of middle-aged and older adults at three European study sites (Barcelona, Spain; Luxembourg, Luxembourg; and Innsbruck, Austria) were analyzed. The dissemination strategies were categorized as digital or traditional. Descriptive statistics were used to summarize the dissemination strategies, geographic reach, linguistic adaptation, survey completion levels, how the participants became aware of the survey and costs associated with the dissemination strategies.

Results: The dissemination strategies in the HeBA study followed a mixed approach. While Barcelona (55.7%) and Luxembourg (53.3%) prioritized digital strategies, in Innsbruck, traditional media slightly predominated (52.2%). Digital advertising strategies were the primary source of recruitment in Barcelona (60.8%), flyers or invitation letters in Luxembourg (41.0%), and radio or television reports in Innsbruck (31.6%). Demographic analysis revealed varied distributions of the sex of participants across centers, while consistently showing that both digital and traditional channels predominantly reached the under-65 age group. The global cost per completed survey was lowest in Barcelona (€4.99), followed by Innsbruck (€9.36) and Luxembourg (€17.80).

Conclusion: Digital dissemination proved highly effective in Barcelona, while traditional outreach had greater impact in Luxembourg and Innsbruck. Understanding how participants engage with dissemination channels is important for optimizing recruitment strategies. A balanced mix of digital and traditional dissemination methods is necessary to support successful questionnaire completion. Achieving this balance between reach, engagement and costs facilitates effective recruitment in population-based studies on neurodegenerative diseases like Parkinson’s disease, as demonstrated by the HeBA study.

Keywords: Parkinson's disease, online health survey, dissemination strategies, participant recruitment strategies, health communication.

INTRODUCTION

Parkinson's disease (PD) affects millions worldwide (1,2) and significantly impacts motor function, cognitive abilities, and overall quality of life (3,4). Early detection and intervention are important for improving patient outcomes and developing effective therapies. The European multicenter Healthy Brain Ageing (HeBA) study, aims to identify individuals at risk for PD and other neurodegenerative conditions through a comprehensive online questionnaire (5–7). This questionnaire assesses various risk and prodromal factors, including non-motor symptoms, medical history, and lifestyle factors, which are associated with the development of PD (8–10). Given the scale and objectives of the HeBA study, the effective recruitment of a large-scale, multicenter sample of participants across European countries is necessary. The success of the HeBA study hinges not only on the design of the questionnaire, but also on the strategic implementation of dissemination techniques to reach the target population. This multicenter study, conducted across research centers in Kassel, Germany; Innsbruck, Austria; Barcelona, Spain; and Luxembourg, Luxembourg; comprised two phases: Phase 1, including an online questionnaire (1a) and olfactory testing (1b), and Phase 2, involving in-person evaluations. Kassel utilized a distinct dissemination methodology, where all registered residents of the city and district of Kassel were contacted individually by post. Postal addresses were obtained from the local Residents' Registration Office (7). The other three centers used a combination of distribution strategies.

This study focuses specifically on the initial dissemination phase 1a of the HeBA study, examining the strategies employed in Barcelona, Innsbruck, and Luxembourg. These centers utilized a range of dissemination methods, encompassing both digital approaches (such as social media advertising and website promotions) and traditional approaches (including newspaper, television and radio broadcasts, and printed materials). Our primary goal was to characterize and compare the dissemination strategies adopted by each center, providing insights into the practical implementation

of a large-scale recruitment campaign within the HeBA study. By analyzing the dissemination strategies used in the HeBA study, we aim to provide a guidance on optimizing recruitment methods for similar large-scale, population-based studies in the field of neurodegenerative disease.

METHODS

This study retrospectively analyzes data collected from the HeBA study in Barcelona, Innsbruck, and Luxembourg, covering the period from April 2022 to June 2024.

Data acquisition and management

Data for this study were obtained from three primary sources: (1) the HeBA online survey, (2) records of communication campaigns, and (3) web analytics data. Individual-level data were extracted from the HeBA online surveys administered in each center. In accordance with the privacy and cookie policy, individual survey responses were not tagged with the origin of visit from web analytics data. Instead, participants were asked to voluntarily provide this information at the end of the survey questionnaire. Extracted data included the date of survey access and the participant's self-reported source of information about the study, selected from a list of pre-defined options. Due to variations in the response format for this question across centers (single-choice in Barcelona vs. multiple-choice in Luxembourg and Innsbruck), all reported sources were harmonized into a standardized set of categories for analysis (Supplementary Table S1). All analyses were based on the HeBA dataset version released on October 16, 2024, to ensure consistency, as the database is subject to ongoing updates. Data concerning communication campaigns were compiled from internal records maintained by each center. These records provided information on campaign characteristics such as campaign name, financial expenditure, and the type of media employed. In addition, anonymized

geographic data on visits to the HeBA study landing page were collected using Matomo, a web analytics platform, to identify the geographic origins of initial engagement and illustrate the reach of the dissemination efforts.

Definition of digital and traditional media strategies and how participants learn about the survey

The dissemination strategies employed in the HeBA study were categorized into two primary groups: digital and traditional media. This classification system was applied to all recruitment activities across the centers. A detailed breakdown of the specific methods included in each category is provided in Supplementary Table S2.

Ethical considerations

This study was conducted in accordance with the principles of the Declaration of Helsinki (11) and received ethical approval from the ethics committees at each participating center, and digital informed consent was obtained. The study is registered under the WHO-conform registry number DRKS00025979.

Statistical analysis

Statistical analysis was performed using Python (version 3.12.7) with the pandas (v2.2.3), matplotlib (v3.7.1), seaborn (v0.13.2), and R (version 4.5.0, R Foundation for Statistical Computing, Vienna, Austria) for spatial analysis and geovisualization, using the following packages: dplyr (v1.1.4), sf (v1.0.21), rnaturalearth (v1.0.1), and ggplot2 (v3.5.2).

The analysis included the characterization of dissemination strategies and survey responses. Descriptive statistics (frequencies and percentages) were used to summarize the characteristics of the dissemination strategies employed by each center, including the distribution of digital versus traditional campaigns, the variety of communication channels used, and the target languages of the campaigns. A Sankey diagram was generated to visualize the flow of communication methods, and maps were created to show the geographic distribution of initial web engagement. Finally, a cost analysis was conducted to evaluate the economic cost of the HeBA survey dissemination, calculating the cost per completed questionnaire.

RESULTS

1. Dissemination strategies

1.1. Comparative evaluation of dissemination strategies across study sites

Figure 1A shows the proportional balance between digital and traditional campaigns, while Table 1 provides a detailed breakdown of the specific media types used and their frequencies.

Overall, digital campaigns were the primary approach in Barcelona (55.7%) and Luxembourg (53.3%), whereas traditional media was the main strategy in Innsbruck (52.2%). In Barcelona and Luxembourg, the digital efforts were led by social media advertising (23.8% and 25.4%, respectively). In contrast, Innsbruck's digital strategy was dominated by different websites (40.3%). Across all three centers, newspaper outreach was a key component of the traditional campaigns, accounting for 31.2% of efforts in Barcelona and 29.5% in Luxembourg.

To visualize the flow of communication channels from each center to the specific media types, a Sankey diagram is presented in Figure 1B. This illustrates how each center prioritized different

channels to engage with the target population during the HeBA survey dissemination.

1.2. Language distribution in HeBA dissemination strategies and participant response

Language selection in the HeBA dissemination campaigns varied across centers, aligned with the linguistic landscape of each center, ensuring survey accessibility regardless of the predominant languages spoken. Table 2 presents the distribution of languages used in the campaigns. In Barcelona, materials primarily used Spanish and Catalan, often in bilingual materials (44.8%). Luxembourg displayed a multilingual approach, with German (36.4%), French (28.1%), English (14.1%), and Portuguese (9.1%) as predominant languages. In contrast, Innsbruck exclusively used German (100%).

To assess the reach of these strategies across linguistic groups, we analyzed the language of survey completion for each recruitment channel (Supplementary Table S3). In Barcelona, the majority of participants recruited through digital methods responded in Spanish (89.4%), whereas the majority from traditional methods responded in Catalan (70.2%). In Luxembourg, German was the most frequent language of response for both digital (45.5%) and traditional (47.0%) channels. All recruitment in Innsbruck was in German (100%), consistent with its monolingual campaigns.

2. Performance and cost-related outcomes of dissemination strategies

2.1. Mapping the geographic reach of dissemination strategies

Figure 2 maps the national distribution of survey access points across the three HeBA centers included in this analysis, identified through Matomo analytics. Dot sizes on the maps indicate the frequency of survey access from each location. In Spain, the highest number of accesses originated from the autonomous communities of Catalonia (74.4%), followed by nearby Valencia (15.0%) and the Balearic Islands (4.6%). In Luxembourg, the Capital Region accounted for the majority of survey

accesses (73.8%), with the East of the Alzette region contributing 22.4%. In Austria, the states of Tyrol (58.6%) and Vienna (30.8%) were the primary regions of survey participation.

2.2. Participation metrics in the online survey across HeBA sites (Quantitative performance)

The number of surveys completed at each HeBA center provides insight into participation trends and engagement levels: 9,915 in Barcelona, 8,830 in Luxembourg, and 2,593 in Innsbruck.

Figure 3A illustrates the temporal distribution of number of surveys completed across the three centers, showing the number of accesses per month. Luxembourg displayed a peak in December 2023 (4,759 accesses), while Barcelona and Innsbruck had notable peaks in April 2023 (1,766 accesses in Barcelona and 726 in Innsbruck) and April 2022 (725 accesses in Innsbruck).

Table 3 presents data on how participants learned about the HeBA survey, based on a multiple-choice question included in the questionnaire that explored this aspect. In Barcelona, digital advertising (60.8%) were the most frequently reported source, followed by newspapers (15.7%) and in-person communication (12.9%). Luxembourg participants primarily learned about the survey through flyers or invitation letters which were sent directly to all households (41.0%), followed by email notifications (20.0%) and digital advertising (14.8%). In Innsbruck, radio or television reports (31.6%) were the dominant source, followed by newspapers (28.6%) and digital advertising (16.2%).

2.3. Completeness patterns of online survey respondents (Qualitative performance)

Figure 3B depicts the distribution of survey completion levels among respondents. Completion was defined as the percentage of answered survey items, with surveys classified as high completion (≥ 90% responses), moderate completion (25%–89%), and low completion (< 25%). Most surveys in all centers reached a high completion rate; Luxembourg showed the highest proportion of fully completed surveys (94.5%), followed by Innsbruck (92.6%); and Barcelona (76.8%). The percentage of surveys with low completion (< 25%) was minimal across all centers.

2.4. Demographic profile of participants by dissemination methods

The demographic composition of participants, stratified by sex and age group according to their recruitment method, is presented in Figure 4.

The sex distribution is detailed in Figure 4A. Within the digital channel, the participant distribution was 33.0% male and 67.0% female in Barcelona, 46.5% male and 53.5% female in Luxembourg, and 32.3% male and 67.7% female in Innsbruck. For the traditional channel, the distribution was 32.0% male and 68.0% female in Barcelona, 50.7% male and 49.3% female in Luxembourg, and 40.7% male and 59.3% female in Innsbruck.

Figure 4B presents the age group distribution. In the digital channel, the distribution between the <65 and 65+ age groups was 55.3% and 44.7% in Barcelona, 60.7% and 39.3% in Luxembourg, and 69.5% and 30.5% in Innsbruck, respectively. Within the traditional channel, the distribution between the <65 and 65+ age groups was 65.0% and 35.0% in Barcelona, 63.3% and 36.7% in Luxembourg, and 61.3% and 38.7% in Innsbruck, respectively.

2.5 Dissemination strategy costs per center

Table 4 presents the cost analysis, detailing the total expenditure, number of questionnaires, percentage of completions below and above 50%, and cost per fully completed questionnaire for each center. Barcelona achieved the lowest cost per completed survey (€4.99), followed by Innsbruck (€9.36), and Luxembourg (€17.80).

DISCUSSION

This study evaluated the dissemination strategies employed across three HeBA centers (Barcelona, Innsbruck, and Luxembourg) to recruit participants for an online survey aimed at identifying individuals at risk for Parkinson's disease (PD). The results provide information on the impact of different dissemination strategies on survey participation, geographical reach, and related costs, providing a basis for optimizing future recruitment efforts. A combination of traditional and digital communication channels was employed. Newspaper, radio and television have been commonly used in similar studies (12,13) and continue to be part of dissemination efforts. At the same time, the inclusion of digital tools such as social media and website-based materials reflects recent trends observed in other studies (14–18), which note their ability to support wider and faster access to information. These observations may help guide future planning in similar contexts.

The dissemination strategies were tailored to the specific geographic contexts of each center. This targeted approach resulted in distinct national patterns of initial web engagement with the HeBA survey landing page. Catalonia accounted for the majority of accesses in Spain , the capital region dominated in Luxembourg , and Tyrol was the primary region in Austria. These findings likely reflect the targeted nature of initial dissemination strategies, which were concentrated in these specific regions. It is expected that dissemination strategies will have the most impact near the actual sites where dissemination is implemented. The concentration aligns with research indicating that targeted dissemination leads to increased awareness and access in the specified target area (19). Notably, due to the reach of both traditional and digital media, access points were also observed throughout the rest of each country.

Language selection in the dissemination campaigns was strategically adapted to the unique

sociolinguistic context of each center. This approach aimed to maximize reach of the participants for the HeBA survey. In Barcelona, the use of both Spanish and Catalan reflected the region's official bilingualism. Luxembourg employed a broader multilingual strategy, utilizing not only its three official languages (French, German, Luxembourgish) but also Portuguese and English to specifically engage with its large immigrant communities, thereby reducing potential participation barriers. In contrast, Innsbruck's campaigns were conducted exclusively in German, aligning with the linguistic homogeneity of the Tyrol region. The language participants used to respond the survey showed that the recruitment channel itself was important. In Barcelona, digital channels reached more Spanish speakers, likely because online platforms have a broader, national reach. In contrast, traditional methods recruited more Catalan speakers, suggesting these were more effective at connecting with local communities. In Luxembourg, the mix of languages was consistent across both channels, primarily reflecting the everyday use of German and French, while also successfully reaching English and Portuguese-speaking communities.

Survey participation analysis showed that Barcelona and Luxembourg had the highest total number of surveys recorded. The temporal distribution of survey accesses revealed peaks in different periods across the centers. These variations in survey response can be attributed to specific dissemination efforts. Some peaks seen in Innsbruck and Barcelona (April 2022 and April 2023, respectively) coincided with World Parkinson's Day, when a combination of digital and traditional dissemination campaigns was conducted. This temporal alignment suggests that focusing outreach efforts around specific events can increase participation (20,21). Conversely, in Luxembourg, the largest increase was recorded in December 2023 because of the distribution of invitation letters to all households; possibly making this strategy more effective.

Based on how participants learned about the survey, it is possible to infer which strategies contributed most to increasing the survey visibility across the three centers. Digital advertising

predominated in Barcelona, while flyers or invitation letters were most effective in Luxembourg, and radio or television reports were the primary source in Innsbruck. The effectiveness of traditional mailings in Luxembourg is particularly relevant. Here the recruitment strategy shifted from a predominantly digital approach, performing below expectations, to the more costly direct mailing of invitation letters to all households. While some evidence suggests growing digital literacy among older populations (22,23), these findings indicate that direct, non-digital outreach methods can remain a primary recruitment driver in specific local contexts. These variations reinforce the importance of adapting dissemination strategies to local information ecosystems and cultural norms (24,25).

Dissemination methods reached different demographic groups. For participant sex, the effect of the recruitment channel was not uniform across all centers, suggesting that the relationship between recruitment method and sex distribution may be influenced by local or regional factors. It is worth noting that a higher proportion of female participation was observed in nearly all channels and centers, with the exception of traditional recruitment in Luxembourg. This is a common finding in voluntary health research, where web-based recruitment methods often yield samples with a majority of female participants (13,26). Furthermore, the data show that both digital and traditional methods engaged a larger proportion of participants under 65. This pattern, where digital recruitment attracts younger participants, is consistent with findings from multiple studies that have compared social media to traditional methods and other online registries (22,23,27). These demographic differences, which include the key observation that traditional media also reached a majority of the under-65 cohort, underscore that different recruitment strategies often yield samples that are not directly comparable, reinforcing the challenge of achieving a representative sample through a single method (26,27).

There were significant differences in the cost per completed questionnaire. Barcelona had the lowest cost, followed by Innsbruck , and Luxembourg , which also had the second highest completion rates. These findings suggest that achieving high participation does not always equate to cost of the survey implementation, and that other factors, such as operational efficiency, local macroeconomic factors such cost of living may play a significant role. Future studies should carefully weigh the costs and benefits of different dissemination approaches to optimize resource allocation in accordance with local circumstances.

LIMITATIONS

The interpretation of our findings is subject to some key limitations. While total costs for digital and traditional dissemination were available, we could not calculate a cost-per-completion for each specific strategy. This is because only a subset of participants reported how they learned about the study, and due to the nature of the data collection, completed surveys could not be attributed to a single recruitment channel, as participants may have been exposed to multiple campaigns. Furthermore, the findings on the effectiveness of specific strategies are context-dependent and may not be directly generalizable to other geographic or cultural settings. Finally, the calculation of the cost-per-completion metrics did not directly consider local macroeconomic circumstances, such as cost of living and labor costs. This makes direct comparisons between sites limited in this regard.

CONCLUSIONS

This study of HeBA dissemination strategies across three European centers, demonstrates that the combined and varied use of traditional and digital techniques enabled effective participant engagement and broad survey access. Understanding how participants engage with recruitment channels, addressing geographic and linguistic diversity, and achieving a balance between reach, engagement, and cost considerations are essential for successful recruitment in population-based

neurodegenerative disease studies such as those focusing on PD.

ACKNOWLEDGEMENTS

We would like to thank the participants for dedicating their time.

FUNDING STATEMENT

The HeBA study is supported by a grant from the Michael J Fox Foundation (MJFF) under grant agreement MJFF-PI047794.

CONFLICTS OF INTEREST

D.P.J.: reports funding from The National Secretary for Higher Education, Science, Technology and Innovation of Ecuador – SENESCYT Ph.D. Fellowship Program (DPJ).

P.M.: reports lecture fees from Abbvie, a travel grant from Boston Scientific, and a grant from the MJFF; outside the submitted work.

M.D.C.: reports funding from The National Secretary for Higher Education, Science, Technology and Innovation of Ecuador – SENESCYT Ph.D. Fellowship Program (MDP).

S.G.: reports grants from IMI-Biomap, IMI2 - Call 13, 821511, IHI-IDERHA, IHI - Call 1, 101112135, Horizon-LEOPARD, and EU-Horizon-2.1-HEALTH, 101080964, and MJFF.

A.G.: received support from MJFF (Grant MJFF-010225); and honoraria for lectures from TEVA and Zambon pharmaceuticals and support from UCB Pharma; outside the submitted work.

S.S.: was supported by a PPMI Early-Stage Investigators Funding Program fellowship of the Michael J. Fox Foundation for Parkinson’s Research (MJFF; grant number MJFF-022656). He received salaries from the EU Horizon 2020 research and innovation program under grant agreement No. 863664 and personal speaker’s honoraria from BIAL.

C.T.: received grants EU Horizon 2020 research and innovation program and the DLR ERA-Net and

holds royalties/licences at Thieme Publisher Germany and for the PDSS-2. She received personal payments for consultancy, lectures and advisory boards from Abbvie, Bial, Boehringer, Roche, Ono, STADA, Esteve and UCB. She was supported by and contributes leadership to MDS, IPMDS, EAN, German Neurological Society, Guideline Committees and EURLSSG.

B.M.: has received honoraria for consultancy and/or educational presentations from GE, Bial, Roche, Biogen, AbbVie, Desitin and Amprion. She is member of the executive steering committee of the Parkinson Progression Marker Initiative of the Michael J. Fox Foundation for Parkinson's Research and has received research funding from Aligning Science Across Parkinson's disease (ASAP, CRN).

V.S.: reports grants from IMI-Biomap, IMI2 - Call 13, 821511, IHI-IDERHA, IHI - Call 1, 101112135, Horizon-LEOPARD, EU-Horizon-2.1-HEALTH, 101080964, Elixir-Luxembourg, UNILU, IMI-Immuniverse, IMI2 - Call 15, 853995 and Clinnova and FNR-Luxembourg.

R.K.: received grants from the Fonds National de Recherche (FNR) Luxembourg, Fondation Veuve-Metz-Tesch Luxembourg, the Leir Foundation, MJFF, the European Institute of Innovation and Technology (EIT Health), the Innovative Medicines Initiative (IMI) of the European Union and the European pharmaceutical industry, and the European Union's Horizon 2020 and Horizon Europe research and innovation programs; personal speaker's honoraria and/or travel grants from Abbvie, Zambon and Medtronic. RK has participated as PI or site-PI for industry sponsored clinical trials without receiving personal honoraria.

W.P.: reports personal fees from Alterity, AbbVie, Affiris, AstraZeneca, BIAL, Biogen, Britannia, Lily, Lundbeck, Neuroderm, Neurocrine Denali Pharmaceuticals, Novartis, Orion Pharma, Roche, Takeda, Teva, UCB, Zambon (consultancy and lecture fees in relation to clinical drug development programmes for PD); royalties from Thieme, Wiley-Blackwell, Oxford University Press, Cambridge University Press; grant support from MJFF, EU FP7 & Horizon 2020; outside the submitted work. All other authors declare that they have no conflicts of interest.

DATA AVAILABILITY

The data analyzed in this study are available upon reasonable request from the HeBA data access committee via the first or corresponding author.

AUTHOR CONTRIBUTIONS

1. Research project: (a) Conception: DPJ, PM, MDP, AG, ET, MJM; (b) Organisation: DPJ, PM, MDP, AG, CH, TM, EI, RSL; (c) Execution: DPJ, MDP, AG, PM, CH, TM, EI, RSL, CT, SL; 2. Statistical analysis: (a) Design: DPJ, MDP, SG, KR; (b) Execution: DPJ, MDP, SG, KR; (c) Review and critique: All coauthors; 3. Manuscript Preparation: (a) Writing of the first draft: DPJ, MDC (b) Review and Critique: All coauthors.

ABBREVIATIONS

HeBA: Healthy Brain Ageing

PD: Parkinson's Disease

REFERENCES

1. Pringsheim T, Jette N, Frolkis A, Steeves TDL. The prevalence of Parkinson's disease: A systematic review and meta-analysis. Mov Disord. 2014 Nov;29(13):1583–90. DOI: 10.1002/mds.25945 PMID: 24976103

2. Dorsey ER, Elbaz A, Nichols E, Abbasi N, Abd-Allah F, Abdelalim A, et al. Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol. 2018 Nov;17(11):939–53. PMID: 30287051

3. Schrag A, Jahanshahi M, Quinn N. How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. Mov Disord. 2000 Nov;15(6):1112–8. PMID: 11104193

4. Arie L, Herman T, Shema-Shiratzky S, Giladi N, Hausdorff JM. Do cognition and other non-motor symptoms decline similarly among patients with Parkinson's disease motor subtypes? Findings from a 5-year prospective study. J Neurol. 2017 Oct;264(10):2149–57. PMID: 28879438

5. Horlings C, Garrido A, Vega Moreno C, Schade S, Marques T, Mahlknecht P, et al. The Healthy Brain Ageing (HeBA) Parkinson's disease risk survey: Study design and methods. (Abstract). Mov Disord. 2023;38.

6. Mahlknecht P, Leiter S, Horlings C, Schwarzová K, Egner I, Stockner H, et al. Preferences regarding Disclosure of Risk for Parkinson's Disease in a Population-based Study. Mov Disord Clin Pract. 2024 Nov 18;12(2):203–9. PMID: 39558636

7. Schade S, Ghosh S, Garrido A, Mahlknecht P, Marques T, Horlings C, et al. Identifying individuals at-risk of developing Parkinson's disease using a population-based recruitment strategy: The Healthy Brain Ageing Kassel Study. NPJ Park Dis. 2025;11. PMID: 40681552

8. Heinzel S, Berg D, Gasser T, Chen H, Yao C, Postuma RB, et al. Update of the MDS research criteria for prodromal Parkinson's disease. Mov Disord Off J Mov Disord Soc. 2019 Oct;34(10):1464–70. PMID: 31412427

9. Noyce AJ, Bestwick JP, Silveira-Moriyama L, Hawkes CH, Giovannoni G, Lees AJ, et al. Meta-Analysis of Early Nonmotor Features and Risk Factors for Parkinson Disease. Ann Neurol. 2012 Dec;72(6):893–901. PMID: 23071076

10. Berg D, Postuma RB, Adler CH, Bloem BR, Chan P, Dubois B, et al. MDS research criteria for prodromal Parkinson's disease. Mov Disord Off J Mov Disord Soc. 2015 Oct;30(12):1600–11. PMID: 26474317

11. World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. JAMA. 2013 Nov 27;310(20):2191. PMID: 24141714

12. Dobkin RD, Amondikar N, Kopil C, Caspell-Garcia C, Brown E, Chahine LM, et al. Innovative Recruitment Strategies to Increase Diversity of Participation in Parkinson's Disease Research: The Fox Insight Cohort Experience. J Park Dis. 10(2):665–75. PMID: 32250321

13. Zheng WY, Shvetcov A, Slade A, Jenkins Z, Hoon L, Whitton A, et al. Recruiting Young

People for Digital Mental Health Research: Lessons From an AI-Driven Adaptive Trial. J Med Internet Res. 2025 Jan 14;27:e60413. PMID: 39808785

14. Ali SH, Foreman J, Capasso A, Jones AM, Tozan Y, DiClemente RJ. Social media as a recruitment platform for a nationwide online survey of COVID-19 knowledge, beliefs, and practices in the United States: methodology and feasibility analysis. BMC Med Res Methodol. 2020 May 13;20:116. PMID: 32404050

15. Keat WOL, Gauhar V, Castellani D, Teoh JYC. Tips and Pitfalls in Using Social Media Platforms for Survey Dissemination. Société Int D'Urologie J. 2023 Mar 16;4(2):118–24. DOI: 10.48083/PERG3137

16. Roberts-Lewis S, Baxter H, Mein G, Quirke-McFarlane S, Leggat FJ, Garner H, et al. Examining the Effectiveness of Social Media for the Dissemination of Research Evidence for Health and Social Care Practitioners: Systematic Review and Meta-Analysis. J Med Internet Res. 2024 Jun 5;26:e51418. PMID: 38838330

17. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication. J Med Internet Res. 2013 Apr 23;15(4):e85. PMID: 23615206

18. Hand RK, Kenne D, Wolfram TM, Abram JK, Fleming M. Assessing the Viability of Social Media for Disseminating Evidence-Based Nutrition Practice Guideline Through Content Analysis of Twitter Messages and Health Professional Interviews: An Observational Study. J Med Internet Res. 2016 Nov 15;18(11):e295. PMID: 27847349

19. Brownson RC, Eyler AA, Harris JK, Moore JB, Tabak RG. Getting the Word Out: New Approaches for Disseminating Public Health Science. J Public Health Manag Pract. 2018 Mar;24(2):102–11. PMID: 28885319

20. Thackeray R, Burton SH, Giraud-Carrier C, Rollins S, Draper CR. Using Twitter for breast cancer prevention: an analysis of breast cancer awareness month. BMC Cancer. 2013 Oct 29;13:508. PMID: 24168075

21. Xu S, Markson C, Costello KL, Xing CY, Demissie K, Llanos AA. Leveraging Social Media to Promote Public Health Knowledge: Example of Cancer Awareness via Twitter. JMIR Public Health Surveill. 2016 Apr 28;2(1):e17. PMID: 27227152

22. Corey KL, McCurry MK, Sethares KA, Bourbonniere M, Hirschman KB, Meghani SH. Utilizing Internet-based Recruitment and Data Collection to Access Different Age Groups of Former Family Caregivers. Appl Nurs Res ANR. 2018 Dec;44:82–7. PMID: 30389065

23. Frandsen M, Thow M, Ferguson SG. The Effectiveness Of Social Media (Facebook) Compared With More Traditional Advertising Methods for Recruiting Eligible Participants To Health Research Studies: A Randomized, Controlled Clinical Trial. JMIR Res Protoc. 2016 Aug 10;5(3):e161. PMID: 27511829

24. Chapman E, Haby MM, Toma TS, De Bortoli MC, Illanes E, Oliveros MJ, et al. Knowledge translation strategies for dissemination with a focus on healthcare recipients: an overview of systematic reviews. Implement Sci. 2020 Dec;15(1):14. PMID: 32131861

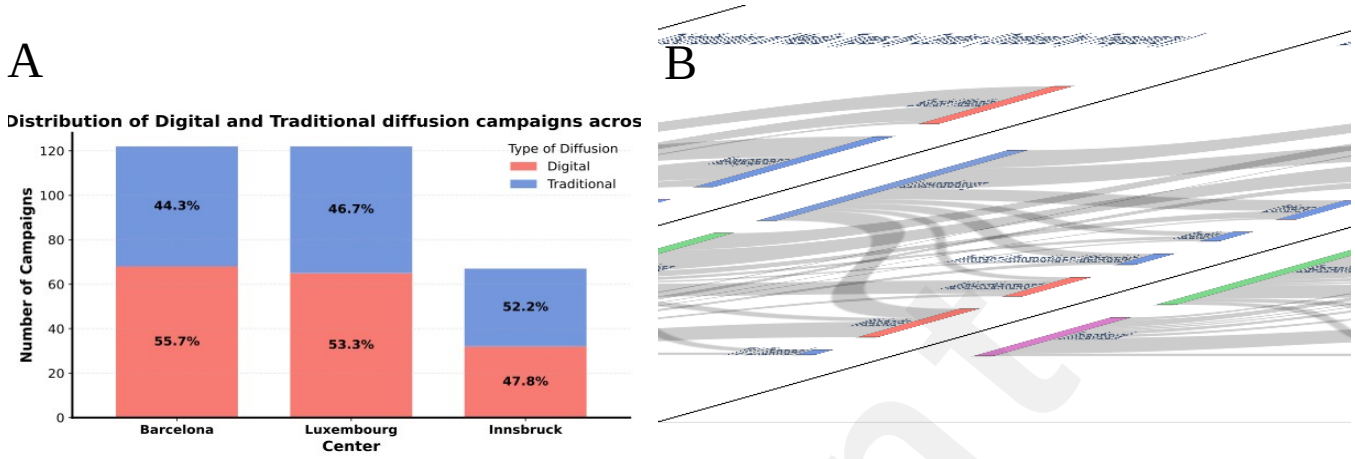
25. Ashcraft LE, Quinn DA, Brownson RC. Strategies for effective dissemination of research to United States policymakers: a systematic review. Implement Sci IS. 2020 Oct 15;15:89. PMID: 33059748

26. Walsh A, Pathak D, Schlegel EC. A Comparative Analysis of Recruitment Methods to Reach Emerging Adults Outside the Clinical Setting. Nurs Res. 2025;74(2):130–5. PMID: 39190397

27. Topolovec-Vranic J, Natarajan K. The Use of Social Media in Recruitment for Medical Research Studies: A Scoping Review. J Med Internet Res. 2016 Nov 7;18(11):e286. PMID: 27821383

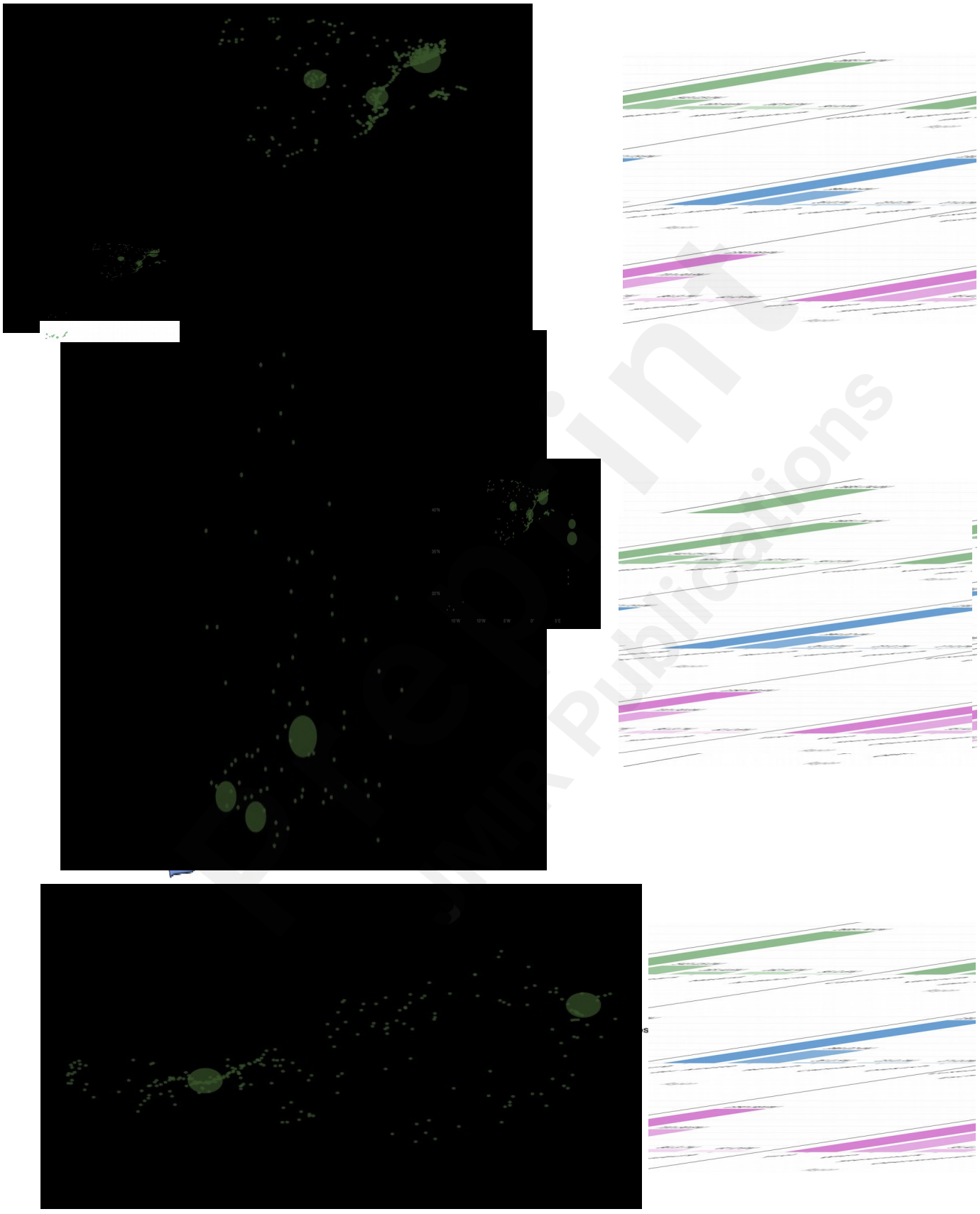
FIGURES AND LEGENDS

Figure 1. Overview of diffusion strategies across HeBA centers



Legend: (A) Distribution of Digital and Traditional diffusion campaigns in Barcelona, Luxembourg, and Innsbruck. (B) Sankey diagram showing the specific communication channels used by each center (Barcelona, Luxembourg, Innsbruck). Digital methods (red) include social media, websites, and digital advertisements; Traditional methods (blue) include newspapers, radio, and TV.

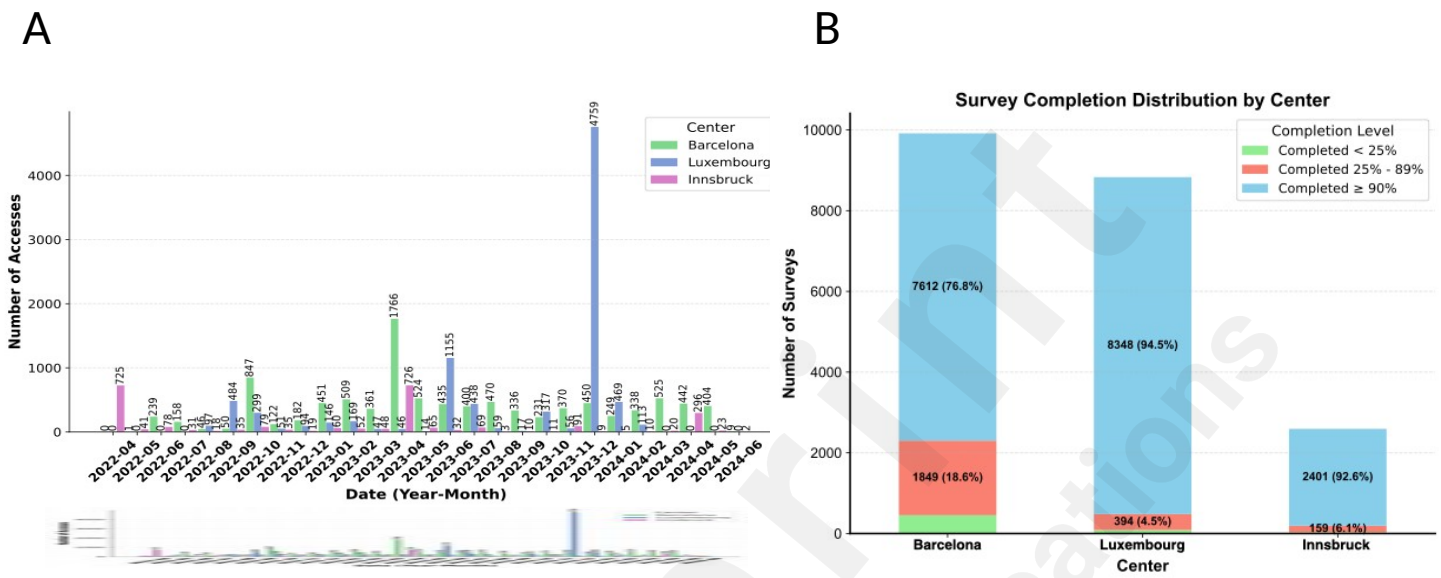
Figure 2: National distribution of web visits to the HeBA survey landing page across centers



Legend: National distribution of initial, anonymous web visits to the HeBA survey landing page. Each center is represented by a distinct color: green for Barcelona, blue for Luxembourg, and pink for Innsbruck. Dot sizes reflect the frequency of visits from each location: small dots indicate fewer

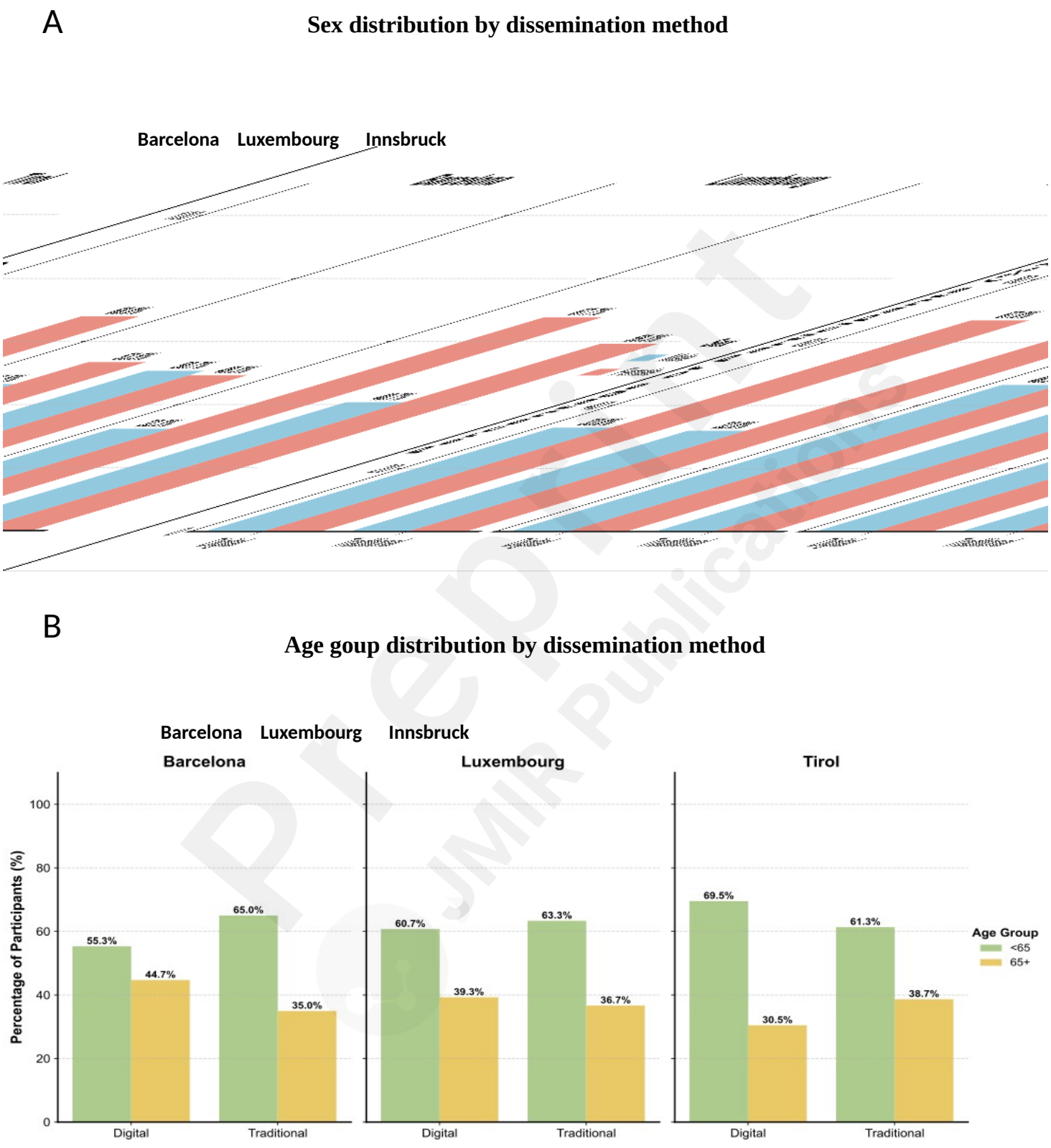
than 100 visits, medium dots represent 100–500 visits, and large dots indicate over 500 visits. The bar charts emphasize the five regions with the most frequent initial interest in each country.

Figure 3: Temporal Distribution of Survey Access and Completion Levels by Center



Legend: (A) Monthly distribution of survey access and completion across the three centers. The number above each bar indicates the total visits for that month. (B) Stacked bar chart showing the distribution of survey completion levels for each center. The sample is categorized into three levels: low completion (< 25%, red), partial completion (25% - 89%, green), and high completion (≥ 90%, light blue). The number and percentage for each segment are shown within the bars.

Figure 4: Demographic Distribution of Participants by Diffusion Method and Center.



Legend: The figure illustrates the demographic distribution of participants recruited via Digital versus Traditional methods across three centers. (A) Shows the sex distribution, where bars represent the percentage of participants within each method. Colors represent sex: sky blue for Male and salmon for Female. (B) Shows the age group distribution. Colors represent age: light green for participants under 65 (<65) and gold for those 65 and older (65+).

TABLES:

Table 1: Distribution of diffusion media and campaign types across HeBA centers

Type of Diffusion	Media	Barcelona n (%)	Luxembourg n (%)	Innsbruck n (%)
Traditional	Newspaper	38 (31.2%)	36 (29.5%)	13 (19.4%)
	Radio	6 (4.9%)	7 (5.7%)	3 (4.5%)
	TV Channel	5 (4.1%)	0 (0.0%)	4 (6.0%)
	Printed Promotional Materials	3 (2.5%)	9 (7.4%)	7 (10.4%)
	Others (Traditional)	11 (9.0%)	13 (10.7%)	3 (4.5%)
	Subtotal Traditional	54 (44.3%)	57 (46.7%)	35 (52.2%)
Digital	Social Media	29 (23.8%)	31 (25.4%)	5 (7.5%)
	Digital Advertisement	23 (18.9%)	5 (4.1%)	5 (7.5%)
	Website	6 (4.9%)	16 (13.1%)	27 (40.3%)
	E-mail	1 (0.8%)	5 (4.1%)	0 (0.0%)
	Subtotal Digital	68 (55.7%)	65 (53.3%)	32 (47.8%)
Total		122 (100.0%)	122 (100.0%)	67 (100.0%)

Legend: Distribution of diffusion media by center, type, and frequency of use, showing each HeBA center's distribution of Digital and traditional media channels. Percentages indicate the relative frequency of each medium within its respective center.

Table 2: Language distribution in HeBA campaigns across centers

Center	Language	n (%)
Barcelona	ES, CAT	52 (44.9%)
	ES	46 (39.7%)
	CAT	18 (15.5%)
Luxembourg	DE	44 (36.4%)
	FR	34 (28.1%)
	EN	17 (14.1%)
	PT	11 (9.1%)
	LU	7 (5.8%)
	FR, DE	5 (4.1%)
	FR, DE, PT, EN, LU	3 (2.5%)
Innsbruck	DE	67 (100.0%)

Legend: Distribution of languages used in HeBA diffusion campaigns by center, showing each language in Barcelona, Luxembourg, and Innsbruck. The languages are represented as follows: **ES** (Spanish), **CAT** (Catalan), **DE** (German), **FR** (French), **EN** (English), **LU** (Luxembourgish), and **PT** (Portuguese). Percentages indicate the relative frequency of language usage per center

Table 3: Comparative analysis of how participants learned about the HeBA survey

How did you find out about	Barcelona	Luxembourg	Innsbruck

this study?			
Newspaper	**920 (15.7%)**	799 (12.6%)	**495 (28.6%)**
Radio or Television report	315 (5.9%)	207 (3.3%)	**548 (31.6%)**
In-person communication	**753 (12.9%)**	475 (7.5%)	223 (12.9%)
Flyer or invitation letter	39 (0.7%)	**2608 (41.0%)**	75 (4.3%)
Digital advertising	**3561 (60.8%)**	**945 (14.9%)**	**281 (16.2%)**
Email	125 (2.1%)	**1272 (20.0%)**	37 (2.1%)
Other	146 (2.5%)	63 (1.0%)	75 (4.3%)
Total	5859 (100.0%)	6369 (100.0%)	1734 (100.0%)

Legend: Comparative breakdown of sources through which participants learned about the HeBA survey across Barcelona, Luxembourg, and Innsbruck. Percentages for Barcelona represent the proportion of participants selecting each source (single-choice question). Percentages for Luxembourg and Innsbruck represent the proportion of total responses for each source, as participants could select multiple options.

Table 4: Cost analysis of HeBA survey completion by Center

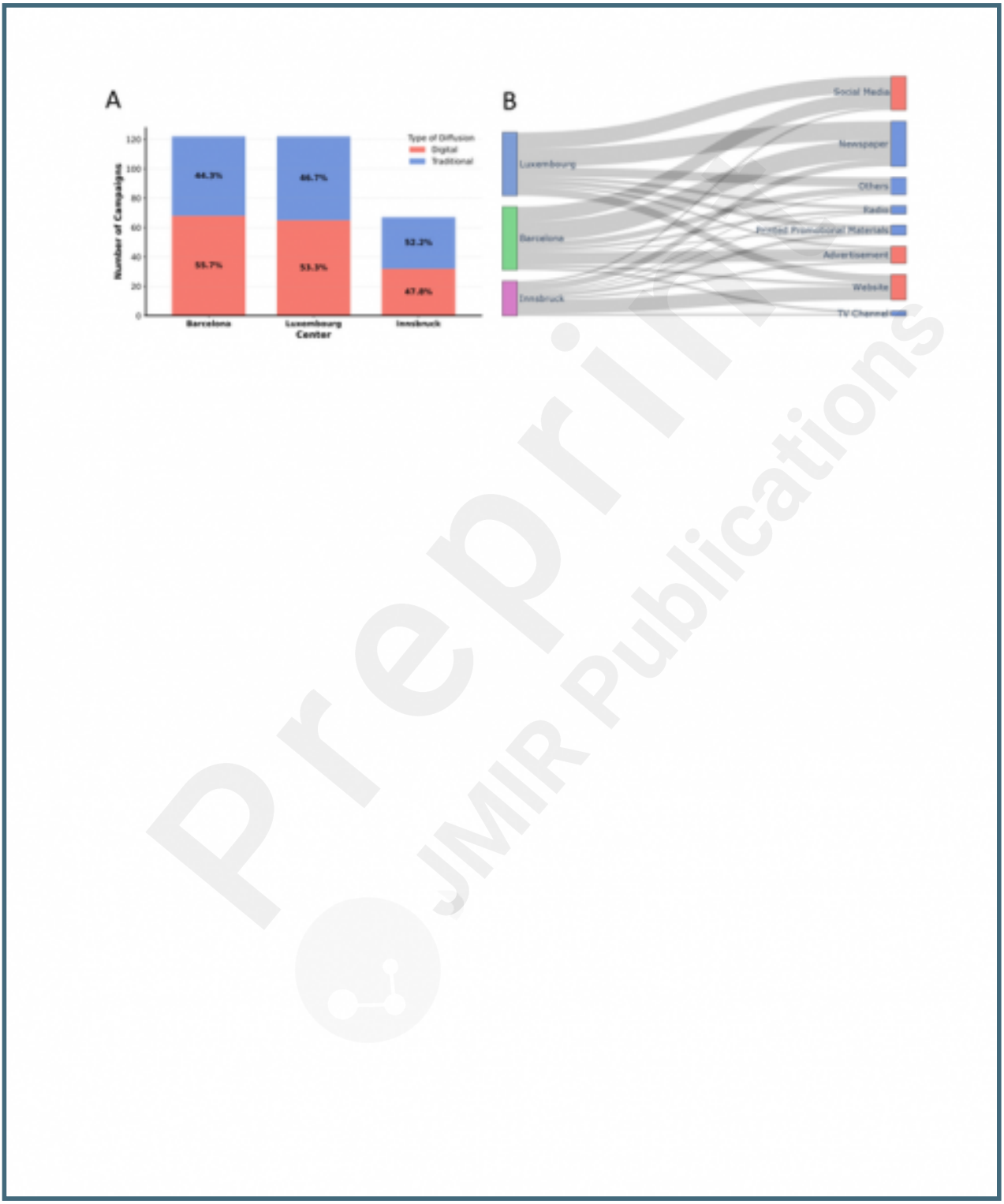
Center	**Completed < 25% n (%)**	**Completed 25% - 89% n (%)**	**Completed ≥ 90% n (%)**	**Cost per Questionnaire (€)**
Barcelona	454 (4,6)	1849 (18,7)	7612 (76,8)	4,99
Luxembourg	88 (1)	394 (4,4)	8348 (94,5)	17,8
Innsbruck	33 (1,3)	159 (6,1)	2401 (92,6)	9,36

Legend: Cost breakdown of HeBA survey data collection across Barcelona, Innsbruck, and Luxembourg. The table presents the total expenditure, the number and percentage of questionnaires by completion level, and the overall cost per questionnaire.

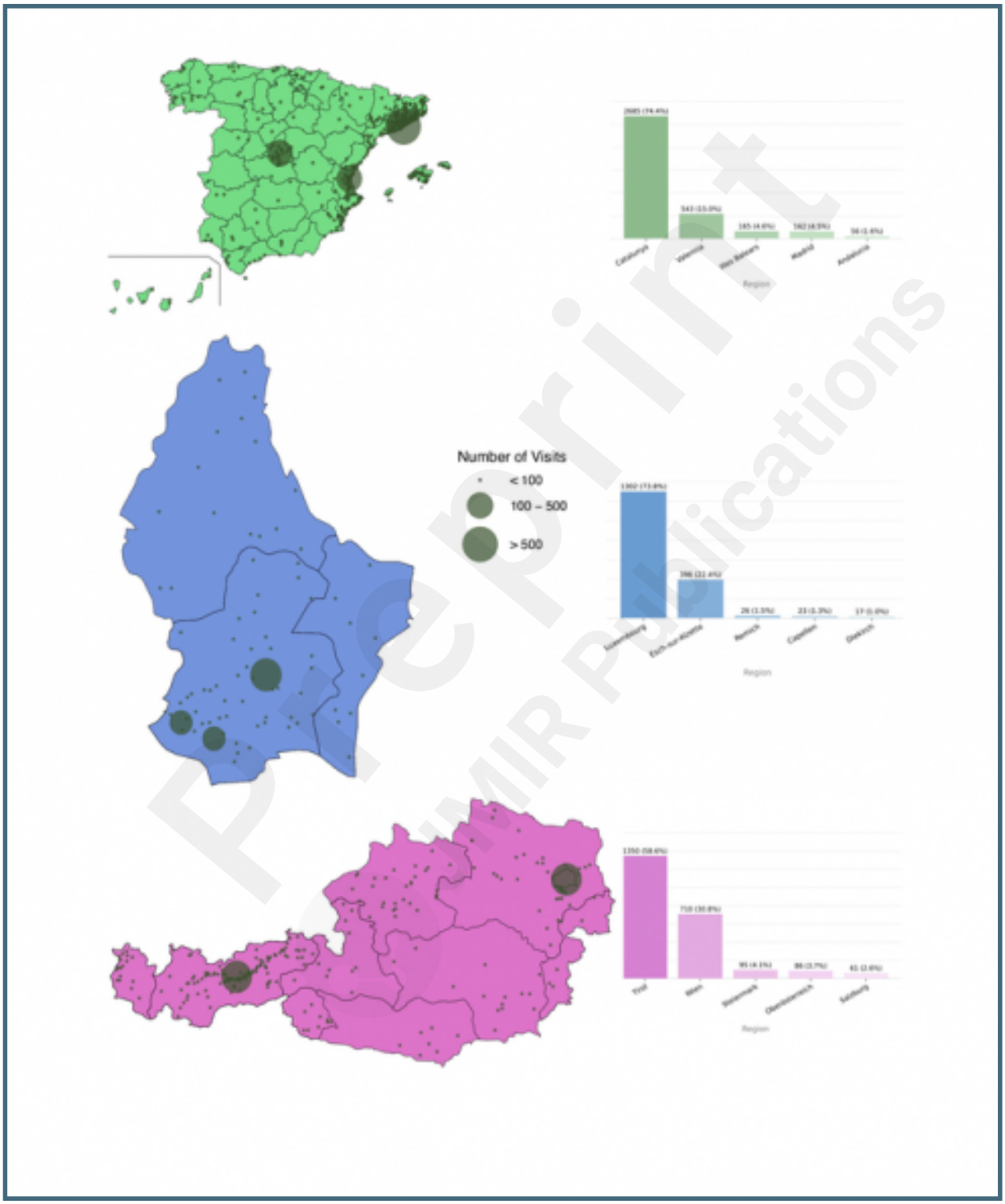
Supplementary Files

Figures

(A) Distribution of Digital and Traditional diffusion campaigns in Barcelona, Luxembourg, and Innsbruck. (B) Sankey diagram showing the specific communication channels used by each center (Barcelona, Luxembourg, Innsbruck). Digital methods (red) include social media, websites, and digital advertisements; Traditional methods (blue) include newspapers, radio, and TV.



National distribution of initial, anonymous web visits to the HeBA survey landing page. Each center is represented by a distinct color: green for Barcelona, blue for Luxembourg, and pink for Innsbruck. Dot sizes reflect the frequency of visits from each location: small dots indicate fewer than 100 visits, medium dots represent 100–500 visits, and large dots indicate over 500 visits. The bar charts emphasize the five regions with the most frequent initial interest in each country.



(A) Monthly distribution of survey access and completion across the three centers. The number above each bar indicates the total visits for that month. (B) Stacked bar chart showing the distribution of survey completion levels for each center. The sample is categorized into three levels: low completion (< 25%, red), partial completion (25% - 89%, green), and high completion (? 90%, light blue). The number and percentage for each segment are shown within the bars.