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► **To cite this version:**

Karin Skill, Ahmed Kaharevic. eHealth in the Hood: Exploring Digital Participation in a Swedish Suburb. 12th International Conference on Electronic Participation (ePart), Aug 2020, Linköping, Sweden. pp.121-132, 10.1007/978-3-030-58141-1_10 . hal-03201952

HAL Id: hal-03201952

<https://inria.hal.science/hal-03201952v1>

Submitted on 19 Apr 2021

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eHealth in the Hood: Exploring digital participation in a Swedish suburb

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Abstract. In this paper we explore digital participation and inclusion in eHealth in a marginalized neighborhood, a suburb, in Sweden and present a survey method where face-to-face interviews in different languages are used. We also use statistics from a regional eHealth application, including data on doctor's visits, as a point of departure for our presentation and analysis of our data on digital participation, usage, and experiences of, and attitudes to digital technologies and services. Furthermore, we address the United Nations' call for disaggregated data on sustainable development and wide inclusion, which correlate to welfare policies at national, regional, and municipal levels and eHealth. We contribute by using a method to explore digital participation, eHealth literacy and attitudes among disadvantaged populations in among hard to survey groups by highlighting differences extracted from disaggregated data on age, ethno-national identification, mother tongue, occupation, and sex. We compare our results with a national survey on internet use, and data from a digital health app used by public sector.

Keywords: digital participation, eHealth literacy, disaggregated data, suburb

1 Introduction: Why surveying the suburb?

As many welfare services are managed in digital channels, we need to understand how people participate and use digital health services, i.e. are included in digital society. eHealth has been among the areas investigated in studies of digital divide [1]. Research on eHealth and digital divide often discusses eHealth literacy among disadvantaged populations, like low income, the elderly, immigrant women or unemployed [2, 3]. eHealth literacy is about “the ability to seek, find, understand and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” [4]. This literacy is like the model on digital divide, presented by van Dijk [1], where motivation, access, competence, and usage are aspects of digital inclusion. Digital participation is often explored with surveys [1, 7]. We know little about digital participation among groups considered hard to survey (that they seldom participate in surveys), like residents in Swedish suburbs [6].

Digital inclusion and participation are central in a democratic welfare state and are also a prerequisite to implement the United Nations Agenda 2030 for transformation with the seventeen accompanying sustainable development goals (SDGs), including a

general ambition to leave no one behind [8]. The UN asks for disaggregated statistical data on progress towards the goals, something that Statistics Sweden aim at contributing [9].

1.1 Previous studies of eHealth, digital participation, and literacy

Previous studies have pointed out that public sector is expected to implement digital solutions to cut costs, and at the same time citizens are expected to make health appointments, find information, and monitor their health in digital channels [2, 3, 4 28]. There are literally thousands of digital applications for diagnosis and care of illnesses, and patients are encouraged to make decisions, book appointments, and follow their cases in digital channels. However, citizens who lack digital literacy may be excluded and experience what Gann calls digital health inequality [2], an aspect of the digital divide. Furthermore, groups of people who experience illness tend to be less digitally competent and less online, which is a challenge for digital inclusion [2]. Digital exclusion seems to be related to social exclusion, aging population, and access to technology or infrastructure [1] and even language [2]. The health centers are collecting data on customer satisfaction through surveys, for example the national patient survey [11]. However, response rates are low in hard to survey groups like residents in Swedish suburbs [6, 12], and there is a lack of feedback from surveys on customer satisfaction [11, 13]. When groups in a population do not participate in surveys it is difficult to know what their opinions and attitudes are. To reap the benefits expected from digitalization, as expressed above, inhabitants need to trust digital services and not the least, use them.

1.2 Aim and research questions

The aim of this paper is to explore digital participation around eHealth with a specific survey method in a Swedish suburb considered hard to survey. The research questions are: How do residents use digital technologies and services related to eHealth? What attitudes do residents express towards digital services?

The paper proceeds as follows. First, we motivate the study and give background information about the neighborhood. We describe the application Digital Health Center and data on who uses it. Then we present the survey method and assumptions related to the design of the survey. We compare our results with the nationwide survey *Svenskarna och Internet, (SoI)* performed by Internetstiftelsen [7]. Last, we present results and conclusions on attitudes and practices related to eHealth in the suburb, the hood.

2 Background

Inclusion and participation are central to eHealth, from the ambitions at the UN for sustainable development [8], to Swedish welfare policies [14, 15]. As services are digitalized the local authorities become responsible for taking care of inhabitants who lack digital competence. Initiatives for digital inclusion take place at libraries, citizen centers and study organizations [18, 19]. Lately, citizen centers in Linköping have been

reorganized to care only for digital services provided by the municipality (Kontakt Linköping), which has implied that service for national authorities (i.e. Swedish Public Employment Service, Social Insurance Agency) and their digital services are coordinated elsewhere. The same goes for services provided by the regional authorities such as health services including eHealth. At the local health center in the neighborhood in focus in this paper, Skäggetorp, which is in Linköping, staff considers that many patients in the area do not comprehend Swedish well enough to complete the survey for customer satisfaction, and do not have access to computers where the survey is available in different languages, thus results from the survey are not perceived as fair [13]. When comparing the response rate with other areas in the region the response rate in Skäggetorp is more than twice as low [13]. This requirement to complete surveys directs attention to what can be perceived as good “digitally active” care takers who use digital devices. In a conversation with medical staff at Skäggetorp health center within this study, they emphasized that their impression is that the developers of digital services, like the app Digital Health Center do not comprehend that patients/ residents in Skäggetorp need service through other channels. We need to attend to this indication that people use the Internet and digital services in diverse ways.

2.1 Skäggetorp: description of a marginalized neighborhood

Skäggetorp is a marginalized neighborhood. The Police calls it particularly vulnerable, due to the influence of criminal activities. But this way of characterizing the area and its residents is stigmatizing, and “förorten” i.e “suburb” is a term that many inhabitants prefer, according to studies in similar areas [6]. Indeed, there had recently been shootings in the streets when we performed the study. Yet, we were almost exclusively warmly welcome when we moved around in the area and residents talked about it as their home.

The population is characterized by high numbers of immigrants and there are many different languages spoken. In table 1 statistics about different areas of Linköping municipality are compared to Skäggetorp.

Table 1. Comparison of characteristics in different areas of Linköping municipality [21]

	Inhabitants November 2019	Proportion not born in Sweden 2019	Disposable average household income (SEK) 2017	Proportion liv- ing on income support 2018
Municipality	162 984	18%	354 900	3,4%
Skäggetorp	10 313	56%	250 000	18,0%
Inner city	11 334	15%	327 000	1,8%

2.2 The app Digital Health Center as an example of eHealth

A region is the Swedish authority that is responsible for organizing health care. Since 2018 the Region of Östergötland, where Skäggetorp is located, offers video

appointments through an application (app) called “Digitala Vårdcentralen” (the Digital Health Center). The app is framed as making the health center “always close, wherever you are,” and it is for administration and making appointments that do not require physical meetings, such as counseling, assessments, urgent prescription renewal, as well as physiotherapy. The app is part of the Primary Health center as in many Swedish regions, but there are also private sector alternatives. However, the difference between private and public services are not always clear to the users. To use the app a person must: 1. Download the app (from Google Play or App Store) on a smartphone or digital reader. The app asks for permission to use the device’s camera and microphone 2. Find a date and time that fits 3. Make the appointment by using personal banking ID. The cost is 200 SEK and the same as when visiting the health center in person. For the meeting to start, the user logs on with bankID, a Swedish electronic identification. The check is sent to the address where the user is registered. The app is only provided in Swedish. Regional administrations attempt to cut costs with digital health visits in a similar manner as private companies. The cost of the digital visits supplied by private companies through apps, become part of the cost of the public sector [18]. This way digitalization of public sector is accelerated by developments in private sector. [19]

2.3 Comparison with data compiled from the app Digital Health Center

Data from the Primary Health center in the Region of Östergötland, enable comparison with the health center in Skäggetorp. The number of doctor’s visits in the whole region during February 2019 to January 2020 was 1 567 through the Digital Health Center, and out of them 2 were performed in Skäggetorp [17]. Skäggetorp is among the areas where least doctor’s visits are made with the app. The amount of doctor’s visits in Skäggetorp is very different in comparison to health centers in the center of towns like Motala with 122 visits, and central Linköping with 92 and 91 visits at the two different health centers [20]. The survey by Internetstiftelsen reports that 10% of the respondents use apps for doctor’s visits, and 50% use eHealth services such as renewing medical receipts or reading personal medical records [7]. The low usage of the app in Skäggetorp is a challenge for eHealth.

Skäggetorp has 9 291 persons listed at the health center, while Kungsgatan in central Linköping has 14 036. Based on knowledge about the population who attend the different health centers mentioned above, in terms of average income, share of the population who was born outside of the Nordic countries, share of the population who live on income support, and employment there seem to be a connection between use of the Digital Health Center and above mentioned situation of the population. A similar pattern can be discerned from the data on conversational treatment administered via Internet, where the health centers in the center of Linköping have the highest numbers, while in Skäggetorp the numbers are considerably lower. The Skäggetorp health center has a high degree of accessibility by phone, 99% while Kungsgatan has 93% [17]. Age seems to be of relevance when comparing the amount of appointments done at different health centers – the higher share of people in the age groups 65 and above, the more appointments. Since central Linköping and Skäggetorp have a similar distribution of elderly, it is relevant to compare the number of digital appointments between them.

2.4 A description of the survey method to reach hard to survey groups

The method proposed in this study is a survey technique where people are interviewed face-to-face or by answering questions by themselves on a digital reader/tablet, alternatively in special cases on a paper survey. The selection of respondents is spontaneous. Respondents are recruited by their household door or in public spaces and offered a small cash incentive of approximately 10 Euro for a local grocery store. The inspiration to use a cash check to increase response rates was from housing companies [6].

To participate the respondent should be adult, above 18 years of age, and live in Skäggetorp. Approximately 7 000 adult inhabitants live in Skäggetorp. Our goal was to ask 500 respondents, which we did, and we got a 65% response rate with 323 respondents. Some respondents denied participation due to the number of questions and time required; there were a maximum of 83 questions that took between 10 to 40 minutes or more for someone who needed help to understand the questions and the response alternatives, or wanted to shared experiences related to the questions. The latter is an added value of the method since the interviewer gets contextual information on digital participation about how the respondents reason about the questions and answers. The multilingual interview team could often solve language challenges. However, as has been pointed out in methodological literature, there is a risk of interviewer bias when performing face-to-face survey interviews [20].

2.5 Design of the survey questions and analysis of data

Many questions in our survey are from the nationwide survey of internet usage by Internetstiftelsen [7]. They remark on having problems reaching inhabitants who do not speak Swedish well [7], which was a motivation for our study and our multilingual team. The question about Internet use conditioned other questions about how and for what they use it, and thus people who answered that they do *not* use the Internet did not have to answer these. The use of bankID is an indicator for participation in Swedish digital welfare society and was central. Several questions are from Esaiasson's survey on trust and social cohesion [6]. Two questions about the Digital Health Center were added after conversations with the staff at the health center in Skäggetorp.

From an analytical perspective it is interesting to explore what kind of data people are willing to share when it comes to eHealth. The increase of eHealth has raised concerns for cybersecurity in the health sector [23]. When using a health app, including both private and public ones like the Digital Health Center, users must accept to share their data through their smartphone camera. The issue of surveillance has been raised in different contexts, and in our survey, we included questions from Internetstiftelsen's survey about this. Trust is a central aspect of attitude towards authorities and a dimension of social cohesion [6] and should be acknowledged when services are digitalized. We share descriptive statistics with some cross-tabulation [22].

2.6 Experiences of using the survey method

The cash check distribution has been administered by a student consultancy firm, where students who speak Arabic, Somalian, and Kurdish were recruited. Even if the incentive was important for many, not the least to complete the survey with many questions, there were also some respondents who did not want the cash check.

We have been invited to organizations where local leaders and activists have helped to explain what the survey questions imply. From our meetings with representatives from local authorities and educational organizations, civic organizations, or job coaches we got insights into the way they fill the void of public offices as more and more services are digitalized, and all inhabitants do not comprehend them. They become digital coaches, but they also help with tricky civic activities like filling out a survey. We have worked in the area at different hours of the day all days of the week, even though we have been more active during daytime, when it is reasonable to believe that we encounter people who are at home with kids, elderly, students and people on sick leave, or people who work shifts. We noticed that young people came by in public spaces and asked if they could participate to “make 10 Euro”, while this was not the case when we knocked on household doors. This insight is reflected in the high number of young respondents (90 respondents in the age of 18-25), and in the fact that the response rate differs between public spaces and organizations in comparison to household doors. Still, in Linköping, the share of people aged 18-25 is bigger amongst people born outside of Europe than people born in Sweden [21]. We did not collect personal data to comply with research ethics. The method is time consuming and complex to organize but rewarding in terms of knowledge about digital participation since it contributes with both quantitative and qualitative data.

Through the project we have met people who most likely would not have completed a survey if they had not been approached by an interviewer personally and/or an interviewer who speaks their mother tongue, and due to the cash check of course. But also, people who do not use the Internet and initially felt the study was not meant for them, participated after the interviewer explained that non-users could participate as well.

3 Results and disaggregated data from the survey

We have met with a diversity of respondents in terms of age, sex, country of origin, literacy, mother tongue, occupation, education, digital competence, and usage. The number of respondents was 323 140 participated when we visited households and 193 when we attended public spaces and organizations. To count as possible respondent, the person must understand the purpose of the study, how the survey is performed, and that the participation is confidential and that we did not collect personal data. For 240 interviews we used the survey in Swedish (including orally translated interviews or interviews that were performed in several languages simultaneously with the help of the multilingual interviewing team), 30 used the Arabic, 22 the Somalian, 17 the Bosnian, and 13 the English survey.

Out of all respondents, 281 answered that they use the Internet, and 42 do not. This implies that 13% do not use the Internet. During the interviews we noticed how some

have learned to use one single function on their smartphone, like an app for calls, but are not using any other apps, like bankID. Among those with low literacy, there are of course more difficulties with the use of all text based digital services.

Out of all the respondents 75% uses bankID, in comparison to 84% in Internetstiftelsen's survey [7]. 59% of our respondents feel decision-making is inclusive to a full, high or some extent. This question is from the Agenda 2030 for sustainable development [9]. When it comes to access to technology as van Dijk highlights [1], 81% of the 323 respondents has a smartphone, 16% does not and 3% does not know. 73% has a computer or a tablet, 26% does not, and 1% does not know. Following van Dijk's model, motivation is important apart from physical access. Attitude was explored with the question about feeling part of digital society.

Table 2. Do you feel included in digital society?

	Yes, completely	Yes, largely	Yes, but only a little	No, not at all	I don't know	Total
Number	72	80	72	67	32	323
%	22%	25%	22%	21%	10%	

In comparison with the survey by Internetstiftelsen [7] 9% answered No, not at all on the question expressed in table 2 about feeling included in digital society. In our study 21% reported the same answer. This is among the more interesting differences between our study and theirs. In our survey, the share of respondents who reported not feeling included in digital society is further larger among women than men; 24% of females while 17% of the men reported No, not at all. This is disaggregated data.

3.1 Trust in health centers and concerns about cybersecurity

To be able to analyze the results about eHealth, we include the results about trust in the regular physical health center.

Table 3. Level of trust in the health center per age groups (answer unknown is excluded)

Level of trust	18-25	26-35	36-45	46-55	56-65	55-75	75+	Total
5 and 4 (higher trust)	49%	58%	66%	73%	63%	72%	86%	62%
2 and 1 (lower trust)	20%	18%	22%	17%	24%	16%	7%	19%
Respondents per age group	90	67	58	30	30	32	15	323

As seen in table 3 younger respondents report lower trust in the health center, and reported level of trust raises with age, except in the age group 46-55, which is still higher than in the age group 18-25. The age group 56-65 reports the lowest trust, where 24% report 1 and 2, compared to only 7% in the age group 75+. A crosstabulation with gender shows that females report alternative 5 and 4 slightly more than males, and thus express higher trust.

Of the three largest ethnocultural/national groups in the survey, respondents who identify as Swedish report highest trust (alternatives 5 and 4) in the regular health center, 72%, while 53% of Syrians choose those alternatives, and 58% of the Somalians. Here we recognize that Swedish respondents were older than other groups. The number of respondents who identify as Syrian are considerably fewer than those who identify as Somalian and Swedish. When cross-tabulating trust towards the health center with educational level, no pattern was discernible.

The next table regards surveillance and big companies like Facebook or Google.

Table 4. Number and share of respondents who are concerned that big companies like Facebook or Google intrude into their private integrity on the Internet

	5 Agree	4	3	2	1 Do not agree	No opinion	Total
Number	93	42	44	22	78	44	323
%	29%	13%	13,5%	7%	24%	13,5%	
5+4; 2+1		42%		31%			
SoI*		46%		28%			

*SoI contains data from Internetstiftelsen 2019 for comparison [7].

There are no noteworthy differences between the results from the two surveys (and populations) in table 4 above. This is interesting since there are differences when it comes to the following question regarding the Swedish state and authorities.

Table 5. Number and share of respondents who are concerned that the Swedish state and authorities intrude into their private integrity on the Internet

	5 Agree	4	3	2	1 Do not agree	No opinion	Total
Number	70	45	49	24	96	39	323
%	22%	14%	15%	7%	30%	12%	
5+4; 2+1		36%		37%			
SoI*		21%		51%			

*SoI contains data from Internetstiftelsen 2019 for comparison [7].

There are rather big differences between the results from the survey performed by Internetstiftelsen 2019 [7] and our survey results in the suburb, in table 5. Respondents in the suburb are more concerned that the Swedish state and authorities intrude into their private integrity on the Internet, even if a larger share of the respondents in our survey report 1 Do not agree, than 5 Agree. In comparison with the results on the similar question about concern that big companies intrude, the numbers are similarly polarized.

3.2 Attitude towards Digital Health Center and other eHealth questions

eHealth is partly about sharing of personal data. However, we do not know if respondents connect the Digital Health Center app with sharing of personal data or private integrity. But it has to do with general trust. If users are not willing to share data with the

app, then it could lead to a lower number of digital doctor's visits, it could be a clue into understanding the big difference in actual use of the eHealth app in Skäggetorp and the city center.

Table 6. Number and share of respondents who can imagine using the Digital Health Center app for contacts with doctors, nurses, and physiotherapists

	5 Agree	4	3	2	1 Do not agree	No opinion	Total
Number	106	40	32	22	63	18	281
%	38%	14,2%	11,4%	8%	22,4%	6%	

In table 6, approximately half of the respondents reported 5 or 4 regarding if they can imagine using the Digital Health Center app. There was no illustration of the specific app and we cannot be sure whether respondents interpreted that the question specifically asked for the public sector app Digital Health Center and no other medical apps in general, for example private alternatives.

Results in the cross-tabulation shows that there are no major differences when it comes to sex regarding the question if the respondent could imagine using the app. Internetstiftelsen's survey [7] shows that females use such apps to a higher degree.

The older the age group the less they report imagining using the app. To keep in mind, most respondents belonged to the younger age groups. Of the respondents who reported their health status as "Very good" 60% choose alternative 5 or 4, while the share amongst the group that answers "Good" on health status, is lower when it comes to imagining using the app – 46%. Few respondents answered "Bad" or "Very bad" on the question about their health status. The older age groups report their health status as "Good" more frequently than "Very good". People with poor health status tend to need more health care.

When focusing on the three most reported ethnocultural/national backgrounds we see that Swedes are least likely to imagine using the app and Somalians most likely, nearly twice as likely, as the Swedes. At the same time, respondents who answered Swedish are more commonly found amongst the older age groups than people who reported Somalian. In this context we highlight that the sample was spontaneous in our survey, but the central government agency Statistics Sweden (www.scb.se) shows that in 2018 a significantly lesser share of people born in Africa (4%) are 65 years or older, in comparison with people born in Sweden (21%).

Respondents with an elementary school education or upper secondary school education are more likely to imagine using the app than respondents who started at or graduated from the university. Respondents who graduated from university are least likely. Most of the respondents reported that they have elementary school degree or upper secondary school degree, and some of the respondents reported that they have no schooling at all (and ended up answering the alternative "I don't know"). The number of respondents with academic degrees are rather few. Internetstiftelsen's survey [7] reports that level of education does not affect how many use such apps. However, respondents with lower level of education use other eHealth services (e.g. renewing medical recipe) to a lower degree than respondents with higher education. Regarding

respondents' occupation, respondents searching for a job are slightly more likely to imagine using the app than students and respondents with employment. People who are at home with children are even more likely to imagine using the app. Retired persons are least likely, the same goes for early retirement/sick leave. At the same time, both groups probably need more health care than other respondents. Most respondents in the survey reported either working or studying as their main occupation.

Table 7. Number and share of respondents who find it important to talk to the same staff at the Digital Health Center as they have met in real life at the health center?

	5 Agree	4	3	2	1 Do not agree	No opinion	Total
Number	117	56	30	19	32	27	281
%	42%	20%	10,5%	6,5%	11%	10%	

Taken together 62% reported 5 or 4 on the question in table 7. A person listed at the health center of Skäggetorp might not meet a doctor from that health center if using the Digital Health Center. Instead, the person has access to other doctors in the Region of Östergötland.

The last results we will present in this paper is from a question regarding usage of health or training apps.

Table 8. Number and share who use health or training apps for monitoring and registering what you do at the Internet, e.g. monitoring your pulse or counting steps.

	Several times a day	Daily	Every week	Every month	Some-times	Never	I don't know	Total
Number	34	43	23	13	44	100	24	281
%	12%	15%	8%	4,5%	16%	35,5%	9%	

Taken together 55% of respondents answer that they use a health or training app some-time, as shown in table 8. However, the answer that was reported most frequently was Never (35,5%). According to Internetstiftelsen's survey respondents who are retired find using health/training apps least meaningful, while people with higher income find it most meaningful [7].

5 Conclusions about digital inclusion and eHealth in the suburb

The aim of this paper has been to explore digital participation and inclusion in the area of eHealth with a specific survey method in a Swedish suburb considered hard to survey. We contribute by generating new data about use of digital services and attitudes amongst users that are usually difficult to reach by conventional survey studies such as residents of marginalized areas e.g Swedish suburbs. eHealth has been described as requiring eHealth literacy that includes the ability to seek, find, understand, appraise,

and use information from electronic sources for a health problem. The Digital Health Center app serves as a case of eHealth in this paper.

Our results show that digital participation and inclusion differs in our sample from a suburb, in comparison to results from the sample of Internetstiftelsen, and so too regarding the use of eHealth services. Our disaggregated data on use and attitude differs within and between age groups, sex, ethnicity, education, occupation, and health status. The statistics are descriptive and there are interesting findings regarding trust in health center and attitude towards the Digital Health Center. Groups that report high trust in the physical health center (elderly, Swedes) are also skeptical of the concept. Somalians and younger respondents report a lower trust towards the regular health center but have a more positive attitude towards the app. The relation between trust and attitude towards the app needs further exploration. If we take the call from the UN to get disaggregated data, age seems to be an important identity position. However, this does not explain why the usage of the app is low in Skäggetorp, the residents in the area does not have more elderly inhabitants than other areas in the Region of Östergötland. Neither can the low amount of digital doctor's visits be explained by the attitude towards the app since roughly 50% can imagine using it. The low usage is reflected in the low share of respondents who feel included in digital society. Because eHealth is a part of digital society and the ambition of wide inclusion for sustainable development, the non-use of eHealth services is a part of the digital divide. The low usage needs further exploration.

Then, what attitudes are expressed towards digital and eHealth services in the suburb? The results indicate that the sense of feeling part of digital society is a lot lower in comparison to Internetstiftelsen's survey and could be one clue. The respondents have physical access i.e. Smartphones, banking ID, even if it is lower than in general. A bit more than 50% of the respondents are motivated (i.e. could imagine using it). This raises questions about digital competence or/and eHealth literacy in terms of seeking, finding, understanding, and appraising information. It also raises questions about the requirements for increasing digital inclusion in eHealth, how much focus should be on increasing the digital competence of potential users versus efforts to develop eHealth services that fit a wider range of people with different competences and identity positions.

Future studies could explore the relationship between a trust, belonging, language, and eHealth – this is something that has been raised during the covid19 crisis. Another issue is to map the usage of private health apps in the suburb.

3.3 Acknowledgements

We are grateful to three anonymous reviewers who helped us improve the quality of the paper, and the research council Formas for the planning grant dnr 2018–02366.

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