# E—Mental Health Self-Management for Psychotic Disorders: State of the Art and Future Perspectives

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Objective: The aim of this review was to investigate to what extent information technology may support self-management among service users with psychotic disorders. The investigation aimed to answer the following questions: What types of e-mental health self-management interventions have been developed and evaluated? What is the current evidence on clinical outcome and cost-effectiveness of the identified interventions? To what extent are e-mental health self-management interventions oriented toward the service user? Methods: A systematic review of references through July 2012 derived from MEDLINE, PsycINFO, AMED, CINAHL, and the Library, Information Science and Technology database was performed. Studies of e-mental health self-management interventions for persons with psychotic disorders were selected independently by three reviewers. Results: Twenty-eight studies met the inclusion criteria. E-mental health self-management interventions included psychoeducation, medication management, communication and shared decision making, management of daily functioning, lifestyle management, peer support, and real-time self-monitoring by daily measurements (experience sampling monitoring). Summary effect sizes were large for medication management (.92) and small for psychoeducation (.37) and communication and shared decision making (.21). For all other studies, individual effect sizes were calculated. The only economic analysis conducted reported more short-term costs for the e-mental health intervention. Conclusions: People with psychotic disorders were able and willing to use e-mental health services. Results suggest that e-mental health services are at least as effective as usual care or nontechnological approaches. Larger effects were found for medication management e-mental health services. No studies reported a negative effect. Results must be interpreted cautiously, because they are based on a small number of studies. (Psychiatric Services 65:33–49, 2014; doi: 10.1176/appi.ps.201300050)

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nline therapies (1), Webbased self-management systems (2), and Internet forums (3,4) are rapidly becoming part of the mental health services repertoire. These "e-mental health" technologies are deemed likely to facilitate selfhelp processes (1,5); to lessen risk of stigmatization (1); to offer faster, easier, and more (cost-) effective access to help (1,5–8); and to provide a more neutral space in which service users can speak more freely (1,9). As a consequence, e-mental health care has the potential to support shared decision making, service user empowerment, and self-management (10–13). A review of self-management interventions has shown that computerbased interventions are effective for service users with panic disorders, phobias, and obsessive-compulsive disorders, leading to reduction of symptoms and better quality of life (14). Moreover, most service users seem to appreciate computerized interventions, in particular for enabling them to access services at home whenever they choose (14).

It is, however, unclear to what extent information technology is used to support self-management for people with psychotic disorders. Researchers and practitioners tend to consider psychotic disorders to be less suitable for e-mental health interventions because of the complexity and severity of the disorder (15). Cognitive deficits may limit effective navigation through user interfaces (16), and delusions may

interfere with the use of Webcams, sensors, and other devices (17). So far, only one review has investigated the use of information and communication technology by service users with psychotic disorders (18), and it focused on psychoeducation interventions only. Results indicated that there were no differences in effect on compliance and overall functioning between these technology-based psychoeducation interventions and standard care. This finding is important because it might indicate that e-health interventions may be more cost-effective than standard care if e-health can be implemented with little cost.

In this review, we explore the state of the art of e-mental health care applications for self-management for people with a psychotic disorder. We aimed to answer the following questions: What types of e-health self-management interventions have been developed and evaluated? What is the current evidence on clinical outcome and cost-effectiveness of the identified interventions? To what extent are e-health self-management interventions service user oriented?

### Methods

### Search strategy

We conducted a systematic literature search of the following databases, up to July 2012: MEDLINE, PsycINFO, AMED, CINAHL, and the Library, Information Science and Technology database. We used the terms schizophrenia, schizophrenic, schizoid, schizo-affective, schizoaffective, schizophreniform, schizophrenia\*, schizophrenic\*, schizoid\*, schizo-affective\*, schizoaffective\*, schizophreniform\*, schizomanic, psychosis, psychotic, delusion, delusional, severe mental illness, and severe mental disease. These terms were crossed with computer\*, digital, online, Web, Web-technology, Web-based, Internet\*, Internet portal, Web technology, technology, computer aided, computer facilitated, information technology, CD-ROM, communication technology, interactive, gaming, multimedia, informatics, cell phone, smartphone, mobile phone, ecological momentary assessment, experience sampling, decision support system, decision aid, serious gaming, edutainment, edugame, telehealth, telepsychiatry, telemedicine, e-health, and e-mental health as free text words and medical subject heading terms.

The search was limited to references in English, German, French, and Dutch. Reference lists of retrieved articles were searched for additional relevant studies. The full search strategies can be obtained from the corresponding author on request.

#### **Definitions**

E-mental health was defined as the use of information and communication technology to support or improve mental health care. To define selfmanagement, we used the description introduced by Barlow and colleagues (14): "Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious selfmanagement encompasses the ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life." As reflected in the definition, selfmanagement is a broad concept involving multiple domains.

# Study selection criteria

We included clinical trials as well as observational (feasibility and acceptability) studies because our aim was to provide a comprehensive overview of the interventions developed. In addition, feasibility and acceptability studies offer valuable information for setting future directions for research and development. A study protocol was established before study selection. It was tested on a sample of seven studies and refined accordingly. Articles were included when they described a study focusing on the use of an e-health tool or intervention delivered via a computer, phone or mobile phone, personal digital assistant (PDA), or other device connected to a computer or server, whether Internet based or not for use by persons with schizophrenia or a related psychotic disorder or described a tool or intervention that can help service users with schizophrenia or a related psychotic disorder to manage their illness and well-being and improve their outcomes. Articles had to present original data; that is, reviews were excluded.

Exclusion criteria were studies describing an e-health tool or intervention designed for research or diagnostic purposes only or for use by service users' relatives. Letters, editorials, speeches, posters, comments, book reviews, and theoretical or background articles also were excluded. Furthermore, we excluded articles investigating computer-based cognitive remediation or cognitive enhancement therapy, because good reviews of remediation have already been published (19–22).

In addition, we decided that in case of multiple publications on the same study, the most representative publication (the most recent or complete study or the best study design) was to be included and described in the Results section, with reference to the related publications.

#### Data extraction

Studies were identified and selected by three raters independently (LvdK, LW, and SS). Interrater reliability of the selection of studies, calculated as Fleiss' kappa, was .78, which indicates good reliability (23). Disagreements between the raters were discussed until consensus was reached. [A flowchart of the retrieval procedure and a list of excluded studies are available online as a data supplement to this article.] Data were extracted by one reviewer (LvdK), and a random check was conducted by a second reviewer (SS), which revealed no significant deviations.

### Quality assessment

Quality assessment of the clinical trials was conducted by using the Downs and Black scale (24), which consists of 27 criteria to evaluate both randomized controlled trials (RCTs) and nonrandomized trials. The Downs and Black scale is considered to address the key quality methodological domains important for assessment in the context of systematic reviews (25), covering reporting, external validity, bias, confounding, and power. In the original version of the scale, studies can obtain a maximum of 32 points.

For this study, the original scoring was modified slightly; specifically, the scoring for question 27, dealing with statistical power, was simplified to 1 or 0, as has been done by others (26,27). Consequently, the maximum total score that studies could obtain in this review was 28. The score ranges were grouped into the following four quality levels: excellent (score=26–28), good (score=20–25), fair (score=15–19), and poor (score <15) (26,27).

Three raters (LvdK, LW, and SS) independently conducted the quality assessment. [An overview of ratings is available online in the data supplement.] Interrater reliability—calculated with two-way, single-measure mixed intraclass correlations with absolute agreement—was .72, which is good, according to Cicchetti (28). A quality assessment of acceptability and feasibility studies was not conducted, because there are no validated quality assessment instruments of this kind in this area.

#### Statistical analysis

To calculate effect sizes of the clinical trials, we used Hedges' g coefficient, which is a standardized mean difference, d, multiplied by a correction factor, J, where  $J=1-[3/(4\times df-1)]$ , in which df=df Ntotal-2. Positive values indicated that the intervention condition improved more than the control condition, and we used Cohen's (29) stratification of effect sizes, where .20 is small, .50 is medium, and .80 is large. A metaanalysis was performed when two or more studies could be clustered on the basis of intervention type and when these studies had a similar outcome measure. In case of multiple primary outcome measures, we chose the one that best fit the goal of the intervention type. When multiple control groups were included, we compared the intervention group with the group that received care as usual. In cases where more than one assessment was available, we used the first assessment after the intervention ended. For studies that could not be included in the metaanalysis, we calculated individual effect sizes.

In all cases, the random-effects model was chosen because of anticipated

heterogeneity between research designs. All analyses were performed with version 2 of Biostat's comprehensive meta-analysis program.

#### Results

The search identified a total of 28 studies meeting the inclusion criteria for the systematic review; 14 studies were clinical trials (11 RCTs and three nonrandomized trials), and 14 were feasibility and acceptability studies. Study characteristics and key results are presented in Tables 1 and 2. Our quality assessment revealed that four clinical trials were of fair quality and the remaining trials were of good quality. Across all studies, attrition varied from 0% to 50% and was lowest in studies in which convenience sampling was used as the recruitment strategy.

# E-mental health self-management interventions and outcome

Although the identified self-management interventions showed substantial variability in form, content, and duration, the studies could be clustered according to the self-management components they focused on, as presented below. [Effect sizes of clinical trials, grouped by intervention type, are available in the online data supplement.] Summary effect sizes could be calculated for three intervention types, namely psychoeducation, medication management, and communication and shared decision making. For the remaining intervention types, the number of included studies was not sufficient to calculate a summary effect size.

Psychoeducation. Most studies focused on psychoeducation. Computer programs (available off-line, not via the Internet) examined by Madoff and colleagues (30), Walker (31), and Jones and colleagues (32), as well as the Web portal described by Farrell and colleagues (33), provide general information about schizophrenia and psychotic disabilities, medication, other treatment options, and various community services, such as housing, employment services, and rehabilitation services. Two other studies described computer programs that contain additional interactive parts, such as online psychoeducation therapy groups and a channel for peer support (34,35). An additional study reported results of a so-called "serious game" (36), which is a game designed for an educational purpose, thus combining learning with fun. In this case, the game was designed to enhance service users' understanding of psychosis. In the usage scenario anticipated by the designers, service users could play the game during several sessions at a community mental health center or at home and discuss their gaming experiences afterward with a clinician.

The effect size for e-mental health computerized psychoeducation interventions compared with usual care on the outcome of knowledge was small (Hedges' g=.37; 95% confidence interval [CI]=-.07 to .80), based on three studies (30,32,37).

Medication management. Four studies investigated an e-health tool or intervention directed at management of medication. In the study by Frangou and colleagues (38), service users were provided a medication dispenser that recorded their medication adherence. Every time service users opened the box to take a pill, the medication dispenser transmitted this information via a modem to the computer of the research team. When service users took less than 50% of their prescribed medication, the computer sent an e-mail alert to their clinician. The study by Španiel and colleagues (39) described a mobile phone intervention that aimed to detect early-warning signs of psychotic relapse. Service users in the study were instructed to complete a tenitem Early Warning Signs Questionnaire sent weekly by an automated system to their mobile phones, via short-message system (SMS text message) request. If a certain threshold was exceeded, the service user's psychiatrist received an e-mail alert recommending contacting the client and increasing the dosage of antipsychotic medication by 20%. In these two studies, the interventions primarily enabled better monitoring of service users by clinicians.

The other two studies focused on medication management by promoting a more active role among service users. Beebe and colleagues

Clinical trials of e-mental health interventions for people with psychotic illness

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	-		,				Intervention		Comparison					
Study	Study source	$N_{ m a}$	Sample (% male)	Recruitment ) means <sup>b</sup>	$Study\ design^c$	Study length	Condition <sup>d</sup>	N	Condition <sup>e</sup>	N	Outcome measures <sup>f</sup> F	Key results <sup>g</sup>	Dropout rate <sup>h</sup>	Quality rating <sup>i</sup>
Beebe et al., 2008 (40); also 2004 (62)	U.S.	29	09	Systematic identification	RCT	3 months	TIPS, medication adherence plus usual care	15	Usual care	14 P	(mumber of pills missing from the bottle minus number of pills meanns number of pills mescenhad)	Better medication adherence in intervention group	TIPS, 13%; usual care, 14% (dropout by total invited, 60%)	22 (good)
Brunette et al. (53), 2011	U.S.	41	49	Population- based invitation (flyers, posters, and word of mouth)	Quasi- experimental (convenience sample)	2 months	Web-based decision support system to motivate quitting smoking, plus usual	21	Waiting list	20 N	or a vog	Higher motivation to quit smoking in intervention group	2%	19 (fair)
Frangou et al. (38), 2005	U.K.	108	ন	Systematic identification	RCT	2 months	E-caro medication adherence at home, plus usual care	98	Usual care (N=36); hospital pharmacists monitoring adherence by counting pills, plus usual care (N=36)	27	Medication adherence; PANSS, CGI; resource utilization	Better adherence in e-monitoring versus control groups; better PANSS score in e-monitoring and pill counting groups versus usual care; better CGI scores in e-monitoring group versus group versus hoth control group versus group versus group versus mitervention group had fewer general	Not reported (dropout by total invited, 43%)	22 (good)
Jones et al. (32), 2001	U.K.	112	67	Population- based invitation (letter from health care service)	RCT	6 months	Computer-based psychoeducation only	26	Usual care (psychoeducation by community psychiatric nurse) (N=28); combination psychoeducation by computer and community psychiatric nurse (N=28)	S 92	Satisfaction; KISS, BPRS; ITAQ; GAF; cost- effectiveness	Cost higher in the intervention group; no other differences between groups	Computer, 41%; combination, 29%; usual care, 54% (dropout by total invited, 51%)	19 (fair)

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Table 1 Continued fr	Table 1           Continued from previous page	1ge												
							Intervention		Comparison					
Study	Study source	$\mathbf{N}_{\mathrm{a}}$	Sample (% male)	Recruitment means <sup>b</sup>	Study design <sup>c</sup>	Study length	Condition <sup>d</sup>	z	Condition <sup>e</sup>	z	Outcome measures <sup>f</sup>	Key results <sup>g</sup>	Dropout $rate^{h}$	Quality rating <sup>i</sup>
Kaplan et al. (55), 2011	U.S.	3000	34	Convenience sampling (Web sites and e-newslists)	RCT	12 months	2 intervention groups: unmoderated Internet peer support Listserv (N=101); unmoderated Internet peer support bulletin board (N=99) (groups merged in	500	Waiting list	100	RAS, Lehman's Quality of Life Interview, Empowerment Scale, MOS, HSCL, questions on frequency of participation acxperiences in intervention	No differences between 3 groups on all outcomes	Listserv, 18%; bulletin board, 10%; waitlist, 12% (data of all 300 service users were analyzed)	23 (good)
Kuosmanen et al. (34), 2009 <sup>k</sup>	Finland	311	28	Systematic identification	Cluster RCT	1 month; 5 sessions	analysis) Computer-based psychoeducation	100	Conventional psychoeducation (N=106); standard care (N=105)	2111 S	groups Self-reported deprivation of liberty; PSS-Fin	No differences between groups; improvement of both measures for all 3 groups	Computer, 3%; usual care, 4%; standard, 4% (dropout by total invited,	24 (good)
Madoff et al. (30), 1996	U.S.	55	54	Systematic identification	RCT	3 months	Computer-based interactive medication instruction	341	Care as usual (medication instruction by a nurse)	21 F	Knowledge retention (test scores) and medication compliance (indicated by telephone)	No differences between groups; both groups scored significantly better in posttest of knowledge retention.	Not reported (dropout by total invited was unknown)	20 (good)
Pijnenborg et al., 2010 (48); also 2007 (69)	Netherlands	62	79	Unclear	Quasirandomized, waitlist-controlled trial: ABA (N=33) and AABA (N=29)	18 weeks	SMS text message prompts to support daily functioning	62	Waiting list	1 62	Percentage of goals achieved	Overall percentage of goals achieved increased in intervention group but dropped after withdrawal	24% of total	21 (good)
Priebe et al. (42), 2007 <sup>m</sup>	Europe (6 countries)	507	îĈ	Systematic identification	Cluster RCT	1 year; intervention every 2 months	Computer- mediated service user- key worker communication (DIALOG)	271	Care as usual (communication without DIALOG system)	236	Quality of life (MANSA); unmet need (CANSAS-P); Client Satisfaction Questionnaire	Between-groups differences on all 3 measures, showing improvement in computer group	Computer, 11%, usual care, 12% (dropout by total invited, 33%)	24 (good)
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<u>:</u>	Quality rating <sup>1</sup>	18 (fair)	18 (fair)	22 (good)	21 (good)	
	Dropout rate <sup>h</sup>	3% of total number of service users (dropout by total invited was unknown)	Not applicable	Intervention, 44%; control, 1% (dropout by total inwited, 64%)	Total, 11% (dropout by total invited, 66%)	
	Key results <sup>g</sup>	Reduction in positive symptoms and increase in schizophrenia knowledge in intervention group	Higher attendance in intervention condition; no difference between subgroups by timing of reminders	No difference between groups on intention-to- treat analysis	Intervention group had longer visits, contributed more actively to the dialogue, had less verbal dominance from chinicians, and had higher patient centeredness ratio	
-	Outcome measures <sup>f</sup>	Scale for the Assessment of Positive Symptoms; KISS; automatically recorded Web site usage	Z	Hospitalization- free survival rate	RIAS for duration of visit, number of statements per visit, clinician verbal dominance, and patient centeredness ratio	
	z	15	648	71	26	
Comparison	Condition <sup>e</sup>	Care as usual (conventional psychoeducation)	2,169 Care as usual	Service users completed a weekly early warning signs questionnaire by mobile phone but no alert emails were sent to investigator	Video about schizophrenia treatment and brochures; no personalized feedback	
	Z	16	2,169	F.	42	
Intervention	Condition <sup>d</sup>	Web-based psychoeducation	SMS text message reminders of mental health appointments either 7 and 5 days prior (N=1,081) or 7 and 3 days prior (N=1,085), plus usual	Mobile phonebased relapse prevention program (TAREPS): service users completed a weekly early-warning signs questionnaire by mobile phone; e-mail alerts sent to	Web-based intervention with personalized feedback to empower service users to discuss treatment with their therapist	
	Study length	12 months	3.5 months	12 months	18 months	
	Study design <sup>c</sup>	RCT	Controlled trial	Double- blind RCT	RCT	
:	Kecrutment means <sup>b</sup>	Systematic identification (clinician referral)	Systematic identification	Systematic identification	Systematic identification (clinical referral)	
-	Sample (% male)	32	44 <sup>P</sup>	26	99	
C	Na (%	$31^{\rm n}$	2,817°	146	<sub>5</sub> 0 <sub>6</sub>	
Ē	Study source	U.S.	U.K.	Czech Republic, U.K.	U.S.	
	Study	Rotondi et al., 2010 (35); also 2005 (71)	Sims et al. (50), 2012	Španiel et al., 2012 (39); also 2008 (72,73)	Steinwachs et al. (46), 2011	

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Table 1

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<u>;</u>	Quality rating <sup>1</sup>	22 (good)
	Dropout rate <sup>h</sup>	Computer, 17%; usual care, 10% (dropout by total invited was unknown)
	$\mathrm{Key}\;\mathrm{results}^g$	Service users in intervention group had better recall of care plans
	Outcome measures <sup>f</sup>	40 Self-developed self-report questionnaires focusing on satisfaction with the treatment planning process; knowledge about care plans
	N	40
Comparison	N Condition <sup>e</sup>	40 Usual care
	N	40
Intervention	Condition <sup>d</sup>	Computer-based decision support to improve service user-clinician communication and treatment planning, plus usual care
	Study design <sup>c</sup> Study length	1 treatment planning trajectory
	Study design <sup>c</sup>	66 Systematic Cluster RCT identification
:	Sample Recruitment (% male) means <sup>b</sup>	Systematic identification
,	Sample (% male)	99
	N <sub>a</sub> (	80.
ē	Study source	U.S.
	Study	Woltmann U.S. et al. (45), 2011

a All participants were adults with a diagnosis of schizophrenia or a related psychotic disorder, unless specified otherwise.

b Recruitment by systematic identification refers to a strategy in which participants were identified in a systematic way, with strict inclusion and exclusion criteria, within one or more departments of a health care service. Recruitment by population-based invitation refers to a strategy in which members of broadly defined populations received an open invitation. Recruitment by convenience sampling refers to a nonprobability method in which participants were selected because they were easy to recruit.

c RCT, randomized controlled trial

d TIPS, telephone intervention for problem solving; SMS, short-message system; ITAREPS, Information Technology-Aided Program of Relapse Prevention in Schizophrenia

e In case of multiple control groups, the first group was included in the analysis.

PANSS, Positive and Negative Syndrome Scale; CGI, Clinical Global Impression Scale; KISS, Knowledge and Information About Schizophrenia Schedule; BPRS, Brief Psychiatric Rating Scale; ITAQ, Insight and Treatment Attitudes Questionnaire; GAF, Global Assessment of Functioning; RAS, Recovery Assessment Scale; MOS, Medical Outcomes Study social support; HSCL, Hopkins Symptom Checklist; PSS-Fin, Patient Satisfaction Scale (Finnish version); MANSA, Manchester Short Assessment of Quality of Life; CANSAS-P, self-rated version of the Camberwell Assessment of Need Short Appraisal Schedule; RIAS, Roter Interaction Analysis System

g Differences refer to statistically significant differences.

h Dropout percentages are based on the number of enrolled service users. In case of recruitment by systematic identification and recruitment by population-based invitation, dropout percentages for the total N based on the number of invited service users are included in parentheses. "Not reported" means that studies did not present figures about eligibility and enrollment.

The maximum possible score was 28, and quality scores were grouped into the following four levels: excellent, 26–28; good, 20–25; fair, 15–19; poor, <15. Schizophrenia spectrum disorder (22%) or affective disorder (78%) k Related publications: Koivumen et al., 2007 (63), 2010 (64); Anttila et al. (65), 2008; Välimäki et al. (66), 2008; Hätönen et al. (67), 2010; Pitkänen et al. (68), 2011

<sup>1</sup> Includes 13 pilot study participants

 $^{\rm m}$  Related publication: Hansson et al. (70), 2008  $^{\rm n}$  Participants were over 14 years old; in addition, the study included 24 support persons.

on N is mental health appointments; 458 (16%) were appointments for service users with a psychotic disorder (mean age of 43 years).

Percentage of appointments with male service users

<sup>q</sup> Participants were over 13 years old; in addition, the study included 20 clinicians.

rarucipants were over 15 years out, in addition, t In addition, the study included 20 case managers.

Feasibility &	and accepta	Feasibility and acceptability studies of e-mental health interventions for people with psychotic illness $^{\mathrm{a}}$	ntal healtn	merivements for p					
Study	Study source	N	Sample (% male)	Recruitment means <sup>b</sup>	Study aim	Intervention or tool	Measurement	Key results	Dropout rate $(\%)^{c}$
Bickmore et al. (41), 2010	U.S.	20 adults	33	Convenience sampling	Evaluation	Computer-based antipsychotic medication adherence system with conversational avatar agent	System use; medication adherence; physical activity; satisfaction	Service users talked to agent 66% of available days; number of days with correct medication intake ranged 8%–100%; walking goals were met 84% of the time;	20
Deegan et al. (44), 2008	. U.S.	189 with severe mental illness (112 adults and 77 young adults), of whom 108 had a psychotic disorder	26	Systematic identification	Evaluation	Interactive computerized shared deciston-making program with support from peer specialist	Log of service users' activities and experiences of focus group (16 service users, 3 peer specialists, 14 case managers, and 4 medical staff)	satisfaction was fight Service users found program helpful and enjoyable; they were willing to disclose information not previously disclosed in face-to-face contact; medical staff and case managers found	of the state of th
Depp et al.	U.S.				Evaluation			program helpful	
(52), 2010 Study 1		8 adults	NR	Unclear		Mobile assessment and cognitive- behavioral therapy	Qualitative assessment of feasibility and acceptability	Service users were using the devices in intended ways; remaining	37
Study 2		9 adults	100	Unclear		Telephone-based skills training and empowerment program to improve everyday living and social skills	Functional outcome <sup>e</sup> ; qualitative assessment of feasibility	Compared with a matched sample, participants showed greater improvement in functional outcomes; feasibility outcome: some participants were concerned that phones may be lost or stolen and kept them in	<b>:</b>
Farrell et al. (33), 2004	U.S.	9 adults with severe mental illness	44	Convenience sampling (volunteering service users)	Development and evaluation	Individualized home page Web portals providing information about health services and community resources	Qualitative usability assessment	a locked cabinet Participants were interested in final design of Web portal and made suggestions for improvement	0

Table 2									
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Study	Study source	Z	Sample Recruith (% male) means <sup>b</sup>	Recruitment means <sup>b</sup>	Study aim	Intervention or tool	Measurement	Key results	Dropout rate $(\%)^{c}$
Gleeson et al. (56), 2012	Australia	NA	NA	NA	Development	Web site for moderated online social therapy, including therapy modules with a social networking function	Testing planned in 2013	Results pending	NA
Haker et al. (3), 2005	Switzerland	576 users of 12 international schizophrenia forums; 58% claimed to be affected, of which 81% stated to suffer from schizophrenia or psychoses	NR	No recruitment; NA	Evaluation	Use of Internet forum for peer support	Percentage of self-help mechanisms (SHMs) and fields of interest (FOI), based on 1,200 forum postings	The most important SHMs were disclosure of personal experience, 48%; providing information, 42%; and request for information, 28%.  Key FOIs were symptoms, medication, or emotional involvement with illness; there were significant differences in SHMs and FOIs with	NA
Killackey et al. (54), 2011	Australia	NA	NA	Systematic identification (with "expressing an interest in intervention" as inclusion criterion)	Development	Internet-enabled mobile application to train for endurance running	Feasibility and acceptability by means of interviews	nonanected persons Results pending	NA
Ku et al. (51), 2007	Korea	10 adults	20	Convenience sampling	Evaluation	Virtual reality-based conversation training, consisting of 4 steps: greetings and introduction, managing conversation, listening and speaking, and ending speaking, and ending	Satisfaction; self- reported feelings of copresence, perceived others' copresence, and social presence	Overall satisfaction moderate (6.3–7.5 out of 10 points); feelings of copresence, perceived others' presence, and social presence were moderate (67.5–71.7 out of 100 points)	0
Myin- Germeys et al. (57), 2011	Netherlands NA	NA	NA	NA	Development	conversation Mobile real-world momentary assessment intervention	NR	Results pending NA Continues on next nage	NA n next nage

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Study	Study source	Z	Sample (% male)	Recruitment means <sup>b</sup>	Study aim	Intervention or tool	Measurement	Key results	Dropout rate $(\%)^{c}$
Sablier et al. (49), 2012	Canada	14 adults	33	Unclear	Evaluation	A PDA-based system for managing activities of daily living	PDA usage for activities and symptoms; satisfaction	Service users carried out a mean of 43% of the activities prompted by the PDA; in 14% of the cases, service users used the PDA to report symptoms;	50
Sherman (43), 1998	U.S.	60 adults with severe mental illness, 30 of whom had schizophrenia or a psychotic disorder	57 62	Systematic identification	Design, development, and evaluation	Computer-based creation of psychiatric advance directives	Satisfaction	Saustaction was row Overall good satisfaction except that service users wanted additional topics covered	35 <sup>f</sup>
Shrimpton and Hurworth (36), 2005	Australia	4; experienced psychoses in late teens, early twenties <sup>g</sup>	NR	Convenience sampling (snowball method)	Design, development, and evaluation	Computer game for education	Open interviews about satisfaction	Service users were enthusiastic and considered the game attractive, but major flaws were revealed, and users suggested complete reworking of the game	$_{ m q}$
van der Krieke et al. (47), 2012	Netherlands 15 adults	15 adults	29	Convenience sampling (snowball method)	Development and evaluation	Web-based support system for routine outcome monitoring	Heuristic evaluation; qualitative assessment of system and advice; satisfaction	Information technology experts reported minor problems, most of which were fixed immediately; service users were able to work with the system and considered the advice meaningful; mean±SD satisfaction score was 73.6±6.6 (out of a maximum of 90)	9

Table 2									
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Study	Study source	Z	Sample (% male	Sample Recruitment (% male) means	Study aim	Intervention or tool	Measurement	L Key results	Dropout rate $(\%)^{c}$
Walker (31), U.K. 2006	U.K.	10 adults	08	Systematic identification	Evaluation	Computer-based psychoeducation	Semistructured satisfaction interviews	Overall good satisfaction: 0 <sup>i</sup> acceptable and enjoyable, little difficulty working with the program; service users could develop a personal relapse prevention plan	

Recruitment by population-based invitation refers to a strategy in which members of broadly defined populations received an open invitation. Recruitment by convenience sampling refers to a nonprobability method in Recruitment by systematic identification refers to a strategy in which participants were identified in a systematic way, with strict inclusion and exclusion criteria, within one or more departments of a health care service. All participants had a diagnosis of schizophrenia or a related psychotic disorder, unless specified otherwise. NA, not applicable because research is ongoing, NR, not reported; PDA, personal digital assistant which participants were selected because they were easy to recruit

Based on the number of enrolled service users. In case of recruitment by systematic identification dropout percentages for the total N based on the number of invited service users are mentioned between brackets. Dropout rate based on 5 invited

Measured by the University of California, San Diego, Performance-Based Skills Assessment

The number invited was unknown.

The user group included professionals as well as 4 service users.

Dropout rate based on 50 invited

(40) described a nursing telephone intervention to support problem solving. Participating service users received a weekly phone call from a nurse. During this phone call, service users were guided in problemsolving processes for a variety of difficulties identified. Furthermore, they received reminders regarding medication and were provided means to assess the effectiveness of coping efforts. Bickmore and colleagues (41) examined a computer-based antipsychotic medication adherence system with an avatar agent installed on a laptop at the service users' homes. After service users powered on the laptop, the avatar started talking to them about their medication use. Service users could respond by clicking a button from a dynamically updated multiple-choice menu. The avatar also taught techniques for selfmaintenance (such as using a multicompartment pill box and a calendar) and encouraged service users to engage in physical activity, such as a 30minute walk.

E-health medication management interventions compared with care as usual had a large effect on medication adherence (Hedges' g=.92; CI=.51-1.33). This finding is based on two

studies (38,40). Communication and shared decision making. Six studies were directed toward improved communication between service user and clinician or toward a process of shared decision making. Priebe and colleagues (42) described a computer program for service users to rate their satisfaction with and need for extra help on eight life domains. The output was interpreted by the clinician and used in a therapy session with the service user. Sherman (43) reported on an intervention with an electronic application to support service users in creating advance directives. Advance directives are documents containing instructions about what actions should be taken in regard to service users' health in case psychosis renders them incapable of making rational decisions. Service users were provided with an interactive presentation about the purpose, types, and pros and cons of advance directives; they were evaluated to determine whether they

Table 3

Types of service user involvement in studies of e–mental health interventions for people with psychotic illness<sup>a</sup>

Study	Reference	Intervention based on service user needs assessment	Service users involved in development	During intervention service users receive feedback on input	Intervention or system is tailored to the service user	Design adapted to target group
Beebe et al. (2008)	40			<b>√</b>	<b>√</b>	NA
Bickmore et al. (2010)	41	_	_	<b>√</b>	1	✓
Brunette et al. (2011)	53	_	_	<b>y</b>	1	<b>√</b>
Deegan et al. (2008)	44	✓	1	1	1	1
Depp et al. (2010)	52	•	•	•	•	•
Study 1	ÿ <u>-</u>	_	_	✓	✓	_
Study 2		_	✓	1	√	1
Farrell et al. (2004)	33	✓	✓	✓	_	✓
Frangou et al. (2005)	38	_	_	1	_	_
Gleeson et al. (2012)	56	✓	✓	1	_	✓
Haker et al. (2005)	3	✓	_	✓	✓	_
Jones et al. (2001)	32	_	_	✓	✓	_
Kaplan et al. (2011)	55	$\checkmark$	_	✓	✓	_
Killackey et al. (2011)	54	_	_	✓	✓	_
Ku et al. (2007)	51	_	_	✓	_	_
Kuosmanen et al. (2009)	34	$\checkmark$	✓	✓	✓	✓
Madoff et al. (1996)	30	_	_	✓	_	_
Myin-Germeys et al. (2011)	57	_	_	✓	✓	✓
Pijnenborg et al. (2010)	48	_	✓	✓	$\checkmark$	_
Priebe et al. (2007)	42	_	_	✓	$\checkmark$	_
Rotondi et al. (2010)	35	$\checkmark$	✓	✓	_	$\checkmark$
Sablier et al. (2012)	49	_	_	_	$\checkmark$	$\checkmark$
Sims et al. (2012)	50	_	_	✓	$\checkmark$	
Sherman (1998)	43	$\checkmark$	✓	✓	$\checkmark$	_
Shrimpton and Hurworth						
(2008)	36	_	_	✓	$\checkmark$	_
Spaniel et al. (2012)	39	_	_	_	_	_
Steinwachs et al. (2011)	46	<b>√</b>	_	√,	✓.	_
Van der Krieke et al. (2012)	47	✓	✓.	√	✓	✓
Walker et al. (2006)	31	_	✓	<b>√</b>	_	_
Woltmann et al. (2011)	45	_	_	✓	✓	✓

<sup>&</sup>lt;sup>a</sup> Reported items are checked (✓); items that were either not reported or reported in the study as not being included are marked with a dash. NA, not applicable

had the capacity to master the information; and they were interviewed about topics they would like to include in their directives. Finally, a copy of the advance directives was printed, including a wallet-sized card stating that an advance directive exists and where to access it.

In the study by Deegan and colleagues (44), service users were provided with an Internet-based computer program that supported them in identifying and formulating their personal values associated with medication use in advance of an appointment with their psychiatrist. If service users needed help using the computer, they received it from a peer. The computer program first explained the concept of recovery and encouraged service users to reflect on their own personal

strategies and means of supporting recovery and wellness. Service users completed a survey inquiring about their symptoms, psychosocial functioning, and medication use. In addition, they were asked about a number of common concerns regarding medication use, and finally, they were encouraged to formulate a personal goal before their psychiatric appointment. After service users completed the various steps, the computer generated a report for them as well as for their psychiatrist, for discussion at their next appointment.

Woltmann and colleagues (45) investigated the feasibility of an application to facilitate shared decision making in care planning. At a computer kiosk in the mental health service facility, clients could use

a touch screen to indicate their personal priorities and ideas for health care services. On the basis of this information, service users could create their personal care plan. After case managers completed a similar process, the two perspectives were merged electronically and discussed in a meeting in which service user and case manager created a final care plan. Steinwachs and colleagues (46) reported about YourSchizophreniaCare, a Webbased intervention that helps service users navigate six areas of care (medication, side effects, referrals, family support, employment, and quality of life). Service users answered questions and were given personalized feedback, including videos of actors recommending how to discuss specific topics with clinicians. In the most

recent study, van der Krieke and colleagues (47) assessed the usability of a Web-based support system that gives service users access to the results of their routine outcome monitoring and provides concrete and personalized advice. The system is designed to support service user participation in medical decision making.

E-health communication and shared decision-making interventions compared with care as usual had a small effect on satisfaction (Hedges' g=.21; CI=.03-.38), a finding based on two studies (42,45).

Management of daily functioning. Five studies investigated e-health tools and interventions aiming at management of daily functioning. Pijnenborg and colleagues (48) investigated a mobile phone intervention in which SMS text messages functioned as prompts to remind service users of the goals they had set for themselves when identifying individual needs during a six-week psychoeducation intervention. The goals that service users chose varied from "taking medication," to "relaxing two hours during the afternoon," to "attending a band rehearsal." In a comparable study, Sablier and colleagues (49) programmed PDAs with prompts to remind service users of their personal schedule of daily activities. Service users could register completed activities and indicate whether they experienced any clinical symptoms. The registered information was sent to the PDA of their caregivers, whose PDA application allowed them to create, modify, and delete date and time of the daily activities of their clients. Sims and colleagues (50) investigated the effect of SMS text messages as reminders to service users of appointments with their clinician.

Another study, by Ku and colleagues (51), examined an intervention consisting of conversational training in a virtual environment with avatars. Service users were presented a virtual social situation, displayed on a big screen, in which they had to go through a scenario of greeting others and introducing themselves, starting the conversation, choosing conversation topics, alternating listening and speaking, and ending the conversa-

tion. In the opening scenario, service users approached a group of people sitting around a table, and they had to decide whether or not they could join the group.

Depp and colleagues (52) described two interventions, one of which is a 24week telephone-based program aimed at increasing social skills and everyday living. Participants received a 20minute phone call from a counselor, who discussed various topics, including service users' well-being, emotions, symptoms, specific skills to reinforce previous training, barriers to practicing skills and achieving goals, and reinforcement of achievements. The other intervention Depp and colleagues described was a mobile phone intervention directed at assessment and cognitive-behavioral therapy for three domains, namely auditory hallucinations, medication adherence, and socialization.

Lifestyle management. Two studies could be classified as focusing on lifestyle management. Brunette and colleagues (53) described a Web-based computer decision support system to encourage service users to quit smoking. The program initially assessed a user's smoking behavior (such as number of cigarettes smoked per day, money spent on tobacco products, and carbon monoxide level) and provided feedback about these measures. Information about the health risks of smoking was presented as an image of the human body with interactive parts. Service users completed exercises that resulted in a summary list of smoking pros and cons, which could be printed out and taken to an appointment with a clinician. Users also were provided an opportunity to discuss matters with a smoking cessation specialist.

Killackey and colleagues (54) described a running fitness program that is Web based for mobile devices. Two freely available applications can be downloaded to an iPod Touch, namely the Couch-to-5K training application (www.coolrunning.com/engine/2/2\_3/181.shtml) and the Nike+ application (nikerunning.nike.com/nikeos/p/nikeplus/en\_EMEA/what\_is\_nike\_plus), which measures running activities through a Nike+ running sensor that is attached to running shoes. Service users

participating in the running program are provided with an iPod Touch, and they can track the distance traveled, the duration of each run, and the pace. Furthermore, they have access to a social networking Web site and a Nike+ account, where training progress is displayed.

Peer support. Two studies investigated the use of online peer-support forums for people with a psychotic disorder (3,55). These forums function as a platform for service users to exchange information and personal experiences with peers, either moderated (55) or not (3). Another study (56) reported the development of a Web site that integrates therapy modules with a private moderated social networking "cafe." The e-cafe functions included a personal profile page, a network of friends, a group problem-solving function, and a discussion forum.

Experience sampling monitoring. Myin-Germeys and colleagues (57) described the development of a PDA-like device called Psymate for monitoring symptoms. The Psymate's primary focus is self-assessment beyond the clinical setting to aid in the treatment of paranoia, hallucinations, negative symptoms, and other problems.

# Cost-effectiveness

Only one study included an economic analysis, which showed that costs of e-mental health self-management interventions were higher than expected because of the lack of computers at service users' homes and the need for transportation to locations with computer facilities (32).

# Orientation of selfmanagement interventions

Table 3 indicates to what extent service users are involved in e-mental health self-management interventions. In almost all interventions described, service users receive feedback on their input, and most interventions or e-health tools are tailored to the individual user. In approximately one-third of the studies, service users were involved in development of the interventions, which were based explicitly on service users' needs, and the design of the e-health tool could be adapted to their usability needs.

#### Discussion

This is the first comprehensive review exploring the area of e-mental health care applications for self-management by service users with a psychotic disorder. Results suggest that people with psychotic disorders are able and willing to use e-health services. Whereas two clinical trials required access to the Internet or a mobile phone and some observational studies used a convenience sample, the vast majority of studies had no special requirements for service users' access to and experience with technological devices. However, attrition rates indicate that this finding should be interpreted with caution. Based on the number of service users enrolled in the study, attrition rates varied from 0% in studies using convenience sampling to 50% in studies with more systematic recruitment strategies. Starting from the total number of service users invited, we found that dropout rates varied from 32% to 65%.

## Types of e-mental health selfmanagement interventions

Our search found a wide variety of interventions, and this diversity indicates that multiple aspects of selfmanagement are being targeted. A theme that seems to be missing from the existing interventions is that of finding meaning and maintaining a positive outlook, which service users have indicated is an important component of self-management (58). Future initiatives for self-management interventions may benefit from taking a recovery approach. A logical step may be to transform parts of the illness management and recovery program (59,60) into e-mental health interventions.

# Evidence base for clinical outcome and cost-effectiveness

The results suggest that e-mental health interventions are at least as effective as standard mental health care, according to the effect sizes of individual studies. [These studies were predominantly on the right-hand side of the forest plot in the online data supplement.] Summary effect sizes indicate that interventions focusing on medication management

and, to a lesser degree, on psychoeducation and on communication and shared decision making are more effective than care as usual or non-technological approaches to mental health care. What should be taken into account, however, is that the care-as-usual conditions were not always clearly described. Moreover, in some trials, usual care was compared with usual care plus the intervention, meaning that the technological approaches functioned as a supplement to routine care. In addition, our calculations were based on very few studies.

Although the results need to be interpreted with caution, the fact that none of the studies showed a negative effect seems promising. The results of our study are partly in line with the outcomes reported by Välimäki and colleagues (18). Their results showed that e-mental health interventions focusing on psychoeducation were as effective as standard care. Furthermore, they reported that technology-based interventions improved medication compliance in the long term. However, the difference in focus and included studies precludes a detailed comparison between our study and that of Välimäki and colleagues (18).

No conclusions can be drawn about cost-effectiveness of e-mental health self-management interventions, because this aspect barely has been addressed in the studies conducted so far. The one study we found that conducted an economic analysis reported higher costs in the intervention condition because computers were purchased for service users. In some studies, costs were not analyzed, but a reduction of costs seemed very plausible, as in the case of text message reminders that significantly decreased the number of missed appointments with clinicians (50).

Lack of evidence can be partly explained by the newness of this field of research. However, some of the usability studies included in our analysis were conducted more than five years ago and have not been followed up by a clinical trial. A reason for this omission may be that e-health projects often entail up-front expenditures of energy and capital for the design and development of the

technological tool, and therefore these projects run the risk of expiring before clinical effectiveness and cost-effectiveness have been investigated. Moreover, conducting RCTs may be particularly challenging in the e-mental health area. Not only are RCTs expensive, but the length of clinical trials may be disproportionate to the rapid developments in the available technology.

Future projects should incorporate clinical and cost-effectiveness analysis in a way that accounts for the dynamic nature of e-mental health interventions. The field may benefit from stepped-wedge research designs or designs that focus on multiple assessments on an individual level. Furthermore, we may need to distinguish between technological interventions that simply computerize existing nondigital methods and innovative interventions. Digital translations of evidence-based nondigital methods are not groundbreaking, but they could be effective in reducing health care costs in the short term. Innovative interventions may maximally exploit the opportunities of e-technology, but they may be less likely to reduce costs in the short term.

# Orientation of selfmanagement interventions

Service user involvement in e-mental health interventions for self-management appears to be not as self-evident as one might expect. User-centered development is as yet not common practice in this population, and in some interventions the clinical perspective predominates. As a result, e-mental health interventions for self-management do not always contribute to service user empowerment. This is a missed opportunity that developers need to account for.

Future technology will provide means of facilitating more intensive and more accurate monitoring of health and health-related behavior. The development of smart and consumer-priced technological devices enables the move toward an era of personalized medicine and the "quantified self." Yet, this move can be for better or worse. Schermer (61) has sketched two possible scenarios: either e-mental health technology will reproduce an

outdated paternalistic paradigm of patient-clinician interaction in which compliance and monitoring are the aim (Big Brother scenario), or it will create a new situation that centers on shared decision making and self-management that adds to the autonomy of service users. One way to increase chances for the latter scenario is to involve service users in conceptual and developmental stages of e-mental health interventions.

Studies summarized in the tables but not discussed are included as references 62–73 in the list of References.

#### Limitations

Our review has a number of limitations. The main limitation is the heterogeneity of results, given the broad definition of self-management. First, there was heterogeneity in control groups. Most individuals in the control groups received care as usual-often a nontechnological intervention—but a detailed description of the control condition was lacking in most cases. Furthermore, there was heterogeneity of study quality, and a comprehensive meta-analysis that included all studies was not possible because of heterogeneity of interventions and outcome variables.

Another limitation is that we were not able to systematically assess the quality of the acceptability and feasibility studies. A suitable assessment instrument that was sufficiently flexible and specific to account for the variety in these studies was not available.

Finally, we note that a publication bias is likely to exist in this area of research. Apart from the fact that positive results are more likely to be published than negative results, we suspect that many e-mental health interventions have not been scientifically investigated. The reason for this is that e-mental health approaches are considered not always to be innovative but simply to be easier, more efficient versions of regular approaches that either have already been proven to be evidence based, rendering new research redundant, or are assumed to be effective (comparable with the implementation of consultation by telephone).

#### **Conclusions**

This review shows that research into the usability and effectiveness of information and communication technology in self-management interventions for people with psychotic disorders has rapidly increased in the past five years. Our findings indicate that e-health interventions are at least equally effective as standard, non-technology-based care. The greatest potential gain of e-health selfmanagement interventions may be to reduce health care costs for service providers as well as service users. To find out whether this assumption is justified, future studies focusing on e-health interventions should include economic analyses.

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Joseph M. Cerimele, M.D., is the editor of this series. Prospective authors—current residents and fellows—should contact Dr. Cerimele to discuss possible submissions. He can be reached at the University of Washington School of Medicine, 1959 NE Pacific St., Box 356560, Seattle, WA 98195 (e-mail: cerimele@uw.edu).

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