

Experience-based Co-design and healthcare improvement: realising participatory design in the public sector

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Abstract

Growing attention has been paid to the potential value of design theory and practice in improving public services. Experience-based Co-design (EBCD) is a participatory research approach that draws upon design tools and ways of thinking in order to bring healthcare staff and patients together to improve the quality of care. Through a six-stage facilitated process, EBCD uses filmed patient narratives to promote change that is grounded in people's experiences and engages participants in co-design activities to implement improvements. The co-design stage is a powerful and yet challenging one, as it requires both staff and patients to renegotiate their roles and expectations. When applied in the healthcare sector design approaches acquire a distinct political dimension by re-configuring the relationships of power between citizens and public services. From a critical review of approximately 60 EBCD projects, we reflect on lessons for effective participatory co-design approaches.

KEYWORDS: Experience-based Co-design, healthcare organisations, participatory design.

Introduction

Applying service design theory and practice in the public sector is an emerging and rapidly growing field. The Design Commission (2013) recently argued strongly in favour of more design input in the shaping of public services. In the healthcare sector - the focus of this paper - the National Health Service Institute for Innovation & Improvement (NHS I²) has since 2005 drawn on design theory, tools and techniques to develop a suite of interventions to help NHS organisations improve the quality of the services they provide (Carr et al., 2009). Whilst attempts at mapping these and other design-led approaches to service

transformation are now under way (see the Service Design Research UK network funded by the Arts & Humanities Research Council), rigorous research into the implementation and impact of service design in the healthcare sector remains fragmented and limited in several important respects. In this paper we reflect on a ten year period that has seen the development, widespread adoption and implementation of one particular approach in the healthcare sector: Experience-based Co-design (EBCD). To inform these reflections we draw on peer reviewed publications and ‘grey’ literature reporting on EBCD projects, as well as the findings from a recent online international survey of those leading such projects, which included 18 follow-up telephone interviews with a sample of the 61 respondents. Our aims in doing so are (a) to explore issues shaping the impact to date of this particular form of participatory co-design in the healthcare sector and (b) to identify lessons for implementations of this and similar co-design approaches in the future.

Experience-based Co-design (EBCD)

EBCD is an approach to improving healthcare services that combines participatory design and user experience design to bring about quality improvements in healthcare organisations. It originated in 2005/06 as a participatory action research approach that explicitly drew on design theory (Bate & Robert, 2007) and was first piloted in a head & neck cancer service at Luton & Dunstable hospital (Bate & Robert, 2008). A recent international survey of completed, ongoing, and planned EBCD implementations in healthcare services found that at least 57 EBCD projects have been implemented following the pilot project in 2005/06, with at least a further 24 projects in the planning stage (Donetto et al., forthcoming). These projects span a broad range of clinical areas (including, but not limited to, emergency medicine, drug & alcohol services, cancer services, paediatric diabetes care and mental health care), not only in the UK but also Canada, the Netherlands, Sweden, Australia, and New Zealand. The number of projects appears to be growing year on year and most of the completed or ongoing projects involve some, more or less structured, form of evaluation. However, with a small number of notable exceptions (Iedema et al., 2010; Tsianakas et al., 2012; Piper et al., 2012; Bowen et al., 2013), robust studies of EBCD projects remain scarce.

Through a ‘co-design’ process the approach entails staff, patients and carers reflecting on their experiences of a service, working together to identify improvement priorities, devising and implementing changes, and then jointly reflecting on their achievements. The EBCD cycle - which typically takes 9 to 12 months - is divided into six stages (Figure 1): (1) setting up the project; (2) gathering staff experiences through observational fieldwork and in-depth interviews; (3) gathering patient & carer experiences through observation and 12-15 filmed narrative-based interviews; (4) bringing staff, patients and carers together in a first co-design event to share - prompted by an edited 20-30 minute ‘trigger’ film of patient narratives - their experiences of a service and identify priorities for change; (5) sustained co-design work in small groups formed around those priorities (typically 4-6); and (6) a celebration and review event (Bate & Robert, 2007; Robert, 2013).

Originally called ‘Experience Based Design’ (EBD) the later switch of title to EBCD was a direct response to observing how early projects - which did typically include extensive work to understand patient experience (much of it innovative at the time) - were paying insufficient attention to the co-design phase; staff were instead relying on traditional, narrower approaches to making improvements to services. As Bowen et al. (2013, p. 243) recently reflected, these early EBD projects were “initiated and led by local managers of

particular services' which gave 'rise to particular configurations of power both in relation to the performance of co-design and in the implementation of changes.'" We shall return to this issue later in this paper.

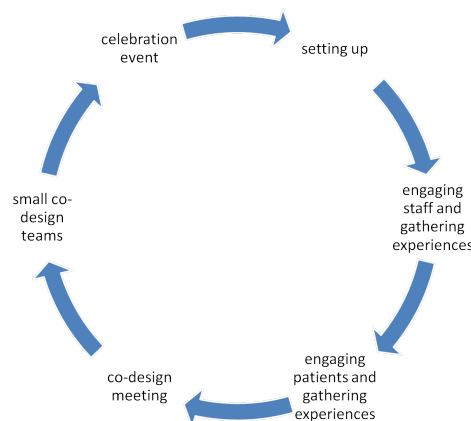


Figure 1 The six stages of the EBCD approach

Subsequent developments have included testing an 'accelerated' version of the approach, developed to address the time and costs involved in producing filmed narratives for the trigger film which drew some criticism from staff. This 'accelerated' version - which relies on the extensive archives of filmed interviews focusing on people's experiences of their health-related conditions held by healthtalkonline (<http://www.healthtalkonline.org/>) - has recently been tested and evaluated in two Intensive Care Units and two lung cancer services (Locock et al., forthcoming) through funding from the National Institute for Health Research. The accelerated approach proved readily acceptable to staff and patients; using films of national rather than local narratives did not adversely affect local NHS staff engagement, and may in some cases have made the process less threatening or challenging. The resulting 48 co-design activities across the 4 services were similar in nature to those in EBCD but achieved more quickly and at lower cost.

Service design, co-design and EBCD

Design principles permeate EBCD. The approach is based on the foregrounding of experience, which is central to user-centred design processes in other fields of application (e.g. from product design to human-computer interaction design) and it makes use of concepts and practical tools - such as touchpoints and emotional mapping - that have long been applied in design (Gage & Kolari, 2002). The focus on patients' and staff's experience rests on the fundamental premise that successful healthcare service design must attend simultaneously to all three dimensions of 'good design' (Berkun, 2004): performance, engineering, and aesthetics, where aesthetics (to which the analysis of experience contributes the most) is not the 'soft' element of the triad but rather encompasses fundamental aspects of a product or service such as utility, usability, and interactivity (Bate & Robert, 2007). Furthermore, design-based and social science perspectives on how to enable in-depth understanding of the meanings and meaning-making practices of individuals and social groups have common origins; combining these can bring theoretical insight to a change intervention aimed at addressing very practical concerns (Bate & Robert, 2008).

Alongside the focus on experience, the other central thread underpinning EBCD is the participatory approach to the co-design processes that aim to bring about quality

improvements. Participatory design gives primacy “to human action and people’s rights to participating in the shaping of the worlds in which they act”, where participation refers to “the fundamental transcendence of the users’ role from being merely informants to being legitimate and acknowledged participants in the design process” (Robertson & Simonsen 2013, pp. 4-5). Participatory design approaches are seen as a way for public services to respond to the increasing pressure from contemporary societal challenges and to address disengagement and disillusion from citizens about politics and democracy (Bradwell & Marr, 2008; Iedema et al., 2010; Lenihan & Briggs, 2011). However, as well as important benefits, co-design as advocated in EBCD presents both conceptual and practical challenges. Below we provide a brief overview of co-design in the context of EBCD before presenting what we know about how it has been applied in EBCD projects to date; finally we discuss the benefits and challenges co-design entails within contemporary healthcare organisations.

Drawing upon participatory design principles, the co-design element in EBCD aims at opening up the boundaries of designing in healthcare services in order to include new stakeholders and forms of expertise; patients are called to share their specialist form of expertise (knowledge) and participate in the design process from the idea generation stage (Sanders & Stappers, 2008). In design science this is part of a major shift towards a new role for designers where “the practice of designing is not exclusive to professional designers” anymore (Carr et al., 2009). It also draws upon the notion of ‘co-creation’ as proposed by Cottam & Leadbeater (2004) entailing the use of distributed resources and the participation of service users as ‘vital to the design and delivery of services, working with professionals and front line staff to devise effective solutions’ (Cottam & Leadbeater 2004, p. 22; see also Meroni & Sangiorgi 2011, p. 20).

In the UK, there is considerable variation in what is termed as ‘co-design’ in different services and sectors, highlighting a range of interpretations and applications of co-design in practice. Co-design is conceptualised, defined and practised differently, ranging from practices such as user testing to feedback and consultation, to online collaboration and/or user research and workshops. The working definition of co-design provided by Bradwell & Marr (2008) leaves room for wide flexibility in how the concept translates into practice but is centred on four elements: participation, development, ownership and power, and outcomes and intent. In the case of EBCD we would operationalise these dimensions as follows:

- » *participation*: co-design is a collaborative process in which as many stakeholders as possible have input;
- » *development*: co-design evolves as a process, maturing and adapting as it takes place;
- » *ownership and power*: co-design involves a transformation of ordinary power relations between stakeholders and aims to generate collective ownership; and
- » *outcomes and intent*: co-design has a practical focus, notwithstanding that unplanned processes and transformations are likely to occur as collateral effects of the process.

In EBCD, the ‘co’ in co-design refers emphatically to partnership and shared leadership between patients and professionals within the NHS (Bate & Robert, 2007). Co-design means more than just being responsive to patients and listening to their needs; patients are not just active partners ‘having a say’ in their care but actively contributing to the design of their care (Bate & Robert, 2007, p. 30).

Co-design and the implementation of EBCD: lost in translation?

A free to access, online toolkit incorporating several case studies has been developed through a collaboration between quality improvement practitioners and academics, and is disseminated through the King's Fund (<http://www.kingsfund.org.uk/projects/ebcd>) charity. The toolkit is divided into 16 sections (for example, 'Interviewing and filming patients' and 'Running the joint patient-staff event'), each of which incorporates film clips of participants in previous projects talking about their experiences and passing on hints and tips for others who may be interested in the approach. Following the initial launch of the toolkit in August 2011 - when it received almost 11,000 views - views of the toolkit have subsequently averaged 3,500 per month (Adams et al., forthcoming).

The survey results indicated that users of the toolkit found it concise and easy to follow, and that it provided them with the practical tools for carrying out an EBCD project. They also highlighted the use of films in the toolkit as a way of demonstrating the experience of patients, staff and carers involved in other EBCD projects. Over 90% of respondents in the survey reported that EBCD 'really engaged patients' and almost 80% said it 'really engaged staff.' However, what is evident from the limited published literature - as well as from analysis of the survey responses - is that the EBCD approach proposed by Bate & Robert (2007) has undergone a variety of adaptations in response to a variety of local contingencies and organisational circumstances. In follow-up telephone interviews with respondents to the international survey (Donetto et al., 2013), it is clear how those leading the implementation of EBCD perceive the approach as inherently flexible, tailoring it to the nature of particular clinical services and their own local contexts:

Our learning re co-design is evolving. Using our first project as an example, we didn't use videos but collected stories through workshops. We had a pre-project workshop to get a mandate for the work. We didn't have separate staff and patient workshops, rather we had joint workshops. We relied strongly on journey mapping and identifying priorities together. We had a strong service design element, utilising the expertise of an external service designer. We also partnered with a bigger project which adopted a traditional PDSA project management approach. Each project since has involved different approach building on our learning and taking into account the situation and the timeframe..

We have already introduced a range of modifications as opportunity or constraints arise. I think EBCD is first a philosophy and only second a method, and methods need to evolve and grow as organisations grow smarter about working with patients/ clients. We use a lot of tools from service design and are evolving ones of our own.

These local adaptations have included the elimination of specific phases particularly - it would appear (Figure 2) - non-participant observation and the celebratory/review event. Beyond these obvious omissions, although over 80% of projects reported conducting patient interviews many have dispensed with the (time- and resource-intensive) filmed component, whilst others have dispensed with one-to-one staff and/or patient interviews and resorted to focus groups. Many of the adaptations we have observed relate to the main criticism of the EBCD approach - it simply takes too long (Figure 3), hence the development and testing of the 'accelerated' approach described above.

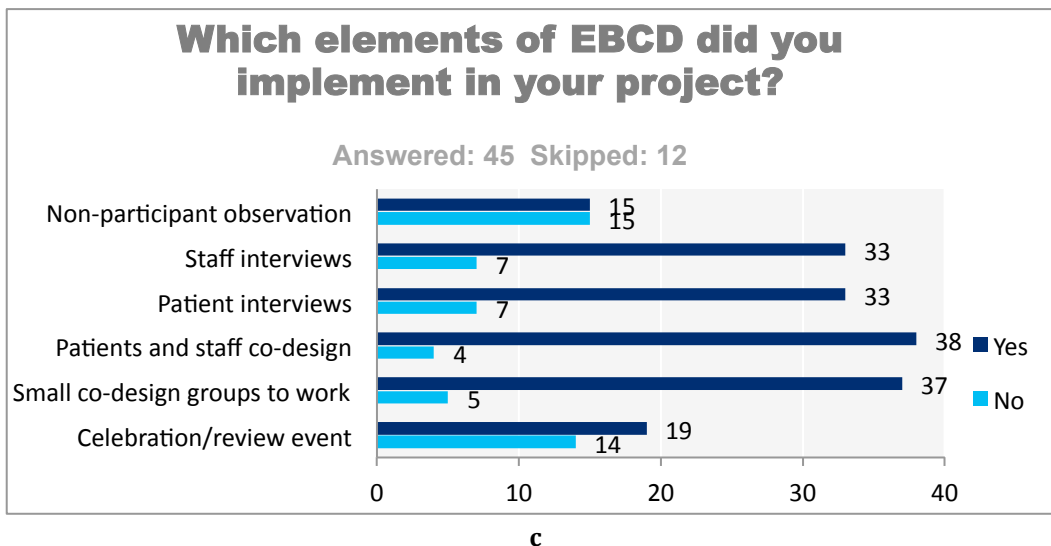


Figure 2. Adaptations to the EBCD approach (source: Donetto et al., forthcoming)

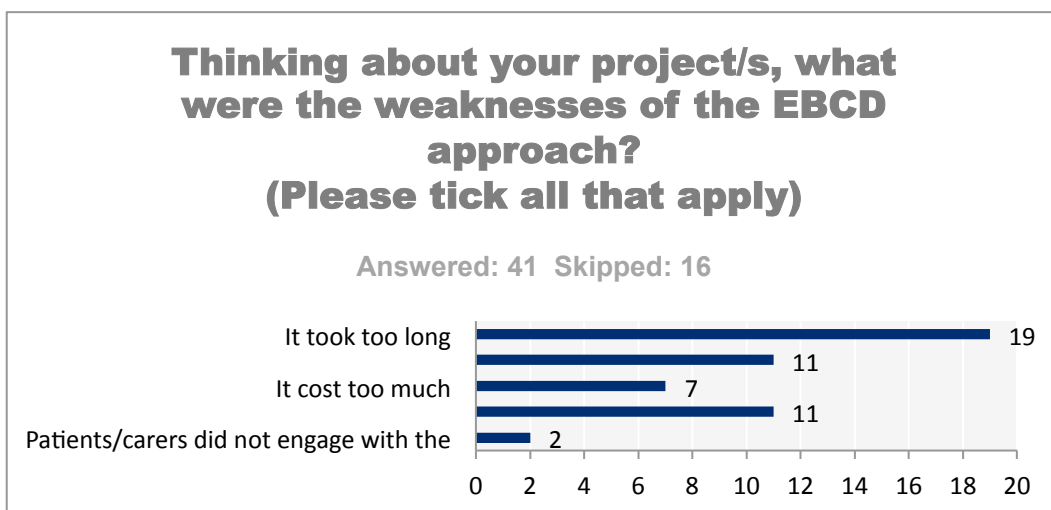


Figure 3. Weaknesses of EBCD approach (source: Donetto et al., forthcoming)

Most significant in our view are the adaptations to the ‘small co-design groups’. It is clear that some of those leading projects are still struggling with the notion of co-design itself, asking in their survey responses for more examples to be provided of co-design meetings and the tools used, more information on how to make co-design events work, the ‘fundamental’ aspects of co-design and where ‘shortcuts’ could be made. Although over 85% of survey respondents reported implementing these as part of their project (Figure 3 above), follow-up telephone interviews revealed a wide range of approaches. Some stark examples included one project which entailed holding just one ‘co-design’ meeting where experiences were discussed and solutions determined but only with patients present; staff were then charged with developing and testing the ‘solution’. Another project leader described how ‘as far as the [small co-design groups], these were mainly staff as most patients felt that they had told us the issues and just wanted to learn what changes we had made.’ This accords with Bowen et al. (2013, pp. 241-242) reflections on the application of EBD in an early case study involving outpatient services for older people suggested that “the modest service improvement that resulted may be due to the specific structuring of participation and the limited ideation tools in EBD”, arguing that a reported “perception of the designing as being something that was done by others” was a key shortcoming in this particular project. Others

reflected on the significance of co-design to which some wished they had paid further attention:

What worked for us was the frequent short meetings, and keeping in close contact. And I think for the patients and relatives to be there kind of held the staff to account, and to their action points. I mean they did divvy things up... there was something about, definitely for staff because of that thing that I said before about that humanistic kind of connection that it really drove them to complete actions.

I think I would probably do more co-design events and sort of do more feedback as you go along really. I think definitely I would have benefitted from more co-design.

The question of expectations of the scale of change that may result from co-design approaches is also an interesting one in the healthcare context; witness the contrasting views of two members of staff in a colorectal cancer service (Adams et al., forthcoming):

[for] the amount of time it takes you need to get some really good stuff out of it ... changing a little bit of [things] work that's good, but is that good enough?

'[People talk about minor but] How minor? ... if that minor change affects 100 people that year, and it's a better experience for 100 people, how wonderful is that?

Bowen et al. (2013) were clearly left a little underwhelmed by the changes brought about in the EBD project they led. There are, of course, several potential reasons why only 'modest' improvements were observed in this particular case (relative expectations being one) but we would certainly agree with the authors that one key area to focus on is the co-design phase of the approach. Interestingly, the authors comment that:

'our own expectations (as participatory designers) about trajectories of change can also be naive when working in unfamiliar and complex organisational contexts. The slow (and uneven) progress from ideas to implementation, and the way that project proposals have been adapted and fused with other inputs to stimulate the actual changes, challenged our own morale and confidence about the impact of the work.'

As noted above the 'accelerated' EBCD (AEBCD) approach led to 48 co-design activities across four services, and these were similar in nature and scale to those typically seen in EBCD (Box 1):

There were 28 activities across the two EBCD pathways, compared to 48 across the four AEBCD examples and a similar distribution of activities, with more small scale changes and process redesign within teams than wider process redesign between services and between organisations. In the EBCD pathways there were: 12 *small scale* changes (e.g. reviewing and improving patient information; regular updates on waiting times in clinic); 12 *process redesign within teams* (e.g. designated phlebotomist to reduce waiting time for blood tests); 2 *process redesign between services* (e.g. physiotherapists reviewed timing to give patients advice about exercise; information flow from pre-assessment to post-surgery redesigned); and 2 *process redesign between organisations* (e.g. link nurse scheme to improve cross-site working and visibility of test results). In AEBCD there were: 21 *small scale changes* (e.g. sourcing clocks to aid patient orientation in ICU; more comfortable v-shaped pillows for post-op patients); 21 *process redesign within teams* (e.g. new private room identified for receiving support after diagnosis; introducing mini 'Schwartz rounds'); 5 *process redesign between services* activities (e.g. changed process for porters to remove waste avoiding ICU rest times; redesigned discharge summary with input from all professions); and 1 *process redesign between organisations* (improved cross-site information booklet for patients transferring to another hospital for surgery)

Box 1. Examples of changes resulting from co-design: EBCD and AEBCD projects (Locock et al., forthcoming)

Although small-scale changes and process redesign within one service area are the most common result of both AEBCD and EBCD (see Box 1), it was observed that small-scale change is often remarkably complex to implement, and what looks like a small change can be immense valuable to patients. Moore & Buchanan (2013) have recently referred to this as ‘sweating the small stuff’. Where successfully implemented, the co-design stages of EBCD have proved powerful but still complex to implement in practice (e.g. Iedema et al., 2010; Piper et al., 2012; King’s Fund, 2011; Boyd et al., 2012). One of the survey respondents commented:

Co-design is very messy, and I'm totally comfortable with that, but it doesn't always work for clinicians in management because their lives are so regulated...they're often very cynical. Cynical in that they've seen everything tried...And probably their empathy, they believe they're empathetic, but they can't afford to be; you just see too much tragedy so you have a detachment that actually gets in the way. What I've found with co-design and particularly the conversation between staff and patients in co-design is the service connotations; it's often the first time they've ever talked with each other that way. So they're often very nervous initially, and I can almost time it, it's almost usually 20-minutes, a kind of a stand off. And then they realise they actually feel the same way, they both feel disempowered and frustrated, and away we go you know. So you know there's a difficulty engaging people, but there's a huge pay off because staff then feel they have a very clear mandate from patients to change things.

In the EBCD projects carried out in Emergency Departments in New South Wales, Australia, co-design demonstrated a number of strengths (Iedema et al., 2010) including: allowing project staff to learn new skills; enabling frontline staff better to appreciate the impact of health care practices and environments on patients and carers; engaging service users in ‘deliberative’ processes that were qualitatively different to traditional forms of engagement; and enabling the service to implement solutions that met the wishes, advice and insights of patients and frontline staff. However, where preparation, recruitment of patients and engagement of front-line staff were not possible or not consistent, co-design worked less well (Piper et al., 2012). In an EBCD project carried out in breast and lung cancer services in the UK, the co-design stages also proved challenging: not all the co-design groups that formed were subsequently maintained and there were issues with the composition of some groups, which ended up including mainly or exclusively managers and clinicians (King’s Fund, 2011). One member of staff considered the emotional demands of working - as clinicians - alongside their own patients in a co-design process (Adams et al., forthcoming):

[The co-design group was] nerve wracking ... I was sitting across a [meeting] table from a woman that I knew, I'd looked at her scan and I was going to have to tell her that her cancer had come back in the next clinic ... and she's telling me how brilliant her life is ...

Another staff perspective on this issue is that - whilst recognising the potential of co-design - it is very challenging for most healthcare staff to move easily between their ‘expert’ and ‘decision-maker’ role to becoming a partner and colleague:

I think that it worked because it was collaborative and there were mixed groups of people doing the work they held each other to account. And kept people on track where perhaps it might have slid... I think people enjoy the bit of collecting stories, it's like consultation, I think that it's harder to do the co-design or collaboration after that initial problem solving phase because I think health professionals are used to being in charge of making things happen.

The complexities of ‘co-design’ at the individual staff member and patient level in the healthcare sector become clearer when considering such insights. Implicit in participatory design approaches is the aim to change power relations but the evidence as to whether or not they do so in the health care setting is very scant; certainly we know little of the circumstances in which they are successful in this regard. Digging a little deeper into the detailed implementation of participatory design approaches such as EBCD often reveals tensions between co-design’s intended aims and its actual forms in practice. The authors involved in carrying out and evaluating several EBCD projects in Australian emergency care services make their own recommendations as to how to improve the co-design processes in EBCD - for example, by involving skilled facilitators, using a mix of involvement strategies, performing a ‘co-design readiness’ assessment, and obtaining recognition from management and policy makers (Iedema et al., 2010). However, what emerges from their and our considerations is that co-design is a complex social intervention whose impact and outcomes are difficult to evaluate and cannot be reduced solely to the design solutions it generates (Bradwell & Marr, 2008; Iedema et al., 2010). Other aspects could include, for example: the personal development of those involved in the process; changes in staff motivation, skills and self-confidence; and the development of trust and new relationships between participants in the process.

Realising participatory design in the healthcare sector

The adoption and implementation of co-design in public services requires critical approaches to both organisational processes and to design practice. When applied in the institutional healthcare setting, participatory design approaches acquire a distinct political dimension by seeking to re-configure the relationships of power between citizens and public services; they cannot be applied as perhaps in the private sector, where power dynamics are not necessarily aiming to be democratic and where hierarchies might not need challenging. We invite design practitioners to share their thoughts on what needs to be borne in mind when using design expertise in the healthcare sector, what their particular form of expertise brings to well established quality improvement processes in large and complex healthcare organisations, and the nature of the critical thinking needs to be applied in order to increase the impact of co-design approaches in this setting.

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